

**QUEST, CHAOS AND RESTITUTION: A QUALITATIVE STUDY OF  
THE EXPERIENCES OF INDIVIDUALS DIAGNOSED WITH  
FIBROMYALGIA SYNDROME**

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## ABSTRACT

**Purpose:** To describe the experiences of individuals recently diagnosed with fibromyalgia syndrome (FMS) using Arthur Frank's narrative typologies

**Relevance:** Fibromyalgia syndrome (FMS) is a musculoskeletal condition of unknown aetiology characterised by chronic widespread pain and poor sleep. There is an absence of studies investigating the illness experience of those recently diagnosed.

**Participants:** A theoretical sampling strategy was used to identify 23 individuals (22 female, 1 male) with a first diagnosis of FMS by a Consultant Rheumatologist.

**Methods:** Qualitative in-depth semi-structured interviews (over a 24 month period) were used to identify the perceptions and experiences of individuals recently diagnosed with FMS. The methodological principles underpinning the study were drawn from pragmatism, critical reflection and feminism (data collection). The design was iterative and emergent.

**Analysis:** Interviews were digitally recorded and transcribed verbatim. Narrative thematic analysis was used to analyse the textual data from the interviews.

**Results:** The experience of being diagnosed and living with FMS is biographically disruptive, threatens identity and challenges patients' understandings of their bodies and the lives they live. Consistent with Arthur Frank's narrative typologies 3 dominant themes of quest, chaos and restitution were identified within the illness experiences of individuals living with FMS. This thesis however challenges Frank's narrative of quest, and proposes the division of this narrative into sub-categories: active engagement and active dis-engagement. Each narrative preference is not uniform but contains common characteristics as it is told through the unique perceptions and experiences of the individual.

**Conclusions:** It is not possible to homogenise the illness experience of individuals with FMS but their narratives contain unifying plotlines. By allowing individuals the opportunity to recount their stories clinicians might recognise these plotlines and understand how the illness experience of FMS is being interpreted.

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## **LIST OF CONTENTS**

<b>ABSTRACT</b>	<b>2</b>
<b>ACKNOWLEDGEMENTS</b>	<b>3</b>
<b>LIST OF CONTENTS</b>	<b>4</b>
<b>LIST OF FIGURES</b>	<b>9</b>
<b>LIST OF TABLES</b>	<b>10</b>
<b>ABBREVIATIONS</b>	<b>11</b>
<b>CHAPTER 1: INTRODUCTION</b>	
1.1 Introduction	12
1.2 Study relevance	12
1.3 Personal background, influences and beliefs	14
1.4 Study aims and objectives	17
1.5 Operational definitions	18
1.6 Methodological approach	18
1.7 Overview of the thesis	18
1.8 Conclusion	21
<b>CHAPTER 2: LITERATURE REVIEW</b>	
2.1 Introduction	22
2.2 Fibromyalgia syndrome: an overview	22
2.2.1 The history	22
2.2.2 Diagnosis	23
2.2.3 Epidemiology	28
2.2.4 Prognosis	30
2.2.5 Aetiology	32
2.2.6 Pathogenesis	33
2.2.7 Patho-physiology	35
2.2.8 Management	38
2.2.9 Quality of life	44
2.2.10 Coping	45

2.3	Patient experiences	47
2.3.1	Experiences of being diagnosed	64
2.3.2	Stigma and illness identity	67
2.3.3	Experiencing struggle	69
2.3.4	Experiencing symptoms of FMS	70
2.3.5	Coping and the process of adaptation	73
2.3.6	Experiences of employment	74
2.3.7	Relationships and the experience of FMS	76
2.4	Conclusion	77

### CHAPTER 3: METHODOLOGY AND EPISTEMOLOGY

3.1	Introduction	79
3.2	Epistemology, methodology and study methods	80
3.2.1	Epistemology	82
3.2.1.1	Pragmatism	85
3.2.1.2	Critical Reflection	94
3.3	Methodology	99
3.3.1	Data collection	101
3.3.2	Sampling decisions	106
3.3.3	Ethical issues	108
3.3.4	Data analysis	112
3.3.5	Rigour	116
3.4	Conclusion	117

### CHAPTER 4: THE STUDY METHOD

4.1	Introduction	120
4.2	The study design	121
4.2.1	The research context	121
4.2.2	Ethics, consent and confidentiality	123
4.2.3	Sample design	124
4.2.4	Sample recruitment	126
4.2.5	Data collection	128

4.2.6	Data analysis	131
4.3	Fieldwork	132
4.3.1	Sampling	132
4.3.2	The semi-structured interviews	134
4.3.3	Data analysis	140
4.3.3.1	Iterative thematic analysis	141
4.3.3.2	Narrative analysis	148
4.3.3.3	Franks' narrative typologies	151
4.4	Conclusion	165
CHAPTER 5: THE RESULTS		
5.1	Introduction	167
5.2	The study participants	170
5.3	Quest, chaos and restitution: the experiences of individuals newly diagnosed with FMS	170
5.4	Restitution narrative	178
5.4.1	An ordinary life	179
5.4.1.1	A reliable and responsive body	180
5.4.1.2	Every day is normal	184
5.4.1.3	A rational explanation	188
5.4.1.4	In search of a diagnosis	195
5.4.2	Knowing what's wrong	200
5.4.2.1	The significance of diagnosis	201
5.4.2.2	Hope of finding a cure	205
5.4.3	Daily living with an invisible illness	210
5.4.3.1	Trying to make visible the invisible	210
5.4.3.2	For every illness there's a remedy?	213
5.4.3.3	The loss of contingency	218
5.5	Chaos	220
5.5.1	The battle to be diagnosed	220
5.5.2	Living with uncertainty	225

5.5.2.1	Limitations of a label	225
5.5.2.2	There is no remedy	227
5.5.2.3	An unpredictable and unresponsive body	230
5.5.2.4	A life out of control	236
5.5.3	Changing visibility	243
5.5.3.1	No-one to listen	243
5.5.3.2	Stigma and identity	245
5.6	Quest	250
5.6.1	The need for change	251
5.6.1.1	Diagnosis as enabler	251
5.6.1.2	Actively re-engaging with life	255
5.6.1.3	Actively disengaging with life	266
5.6.2	Living an acceptable life	271
5.6.2.1	Acceptance of contingency	272
5.6.2.2	Understanding what helps	274
5.6.2.3	The desire for quest stories	278
5.6.2.4	A considered self	280
5.6.2.5	Illness as a positive life event	287
5.7	Conclusion	290
<b>CHAPTER 6: REFLEXIVITY AND THE RESEARCHER POSITION</b>		
6.1	Introduction	291
6.2	Pre-research stage	291
6.3	Data collection	293
6.3.1	Practical issues	294
6.3.2	The researcher as research tool	297
6.3.3	Professional identity	303
6.3.4	Theoretical perspectives	305
6.4	Post-research	307
6.5	Strengths and limitations of the study	308
6.6	Conclusions	312

CHAPTER 7: DISCUSSION AND CONCLUSIONS	
7.1 Introduction	313
7.2 Franks narrative typologies	314
7.2.1 Restitution	315
7.2.2 Chaos	322
7.2.3 Quest	329
7.3 Clinical relevance	333
7.4 Recommendations for future research	335
7.5 Conclusion	335
REFERENCE LIST	336
BIBLIOGRAPHY	369
APPENDIX 1: The American College of Rheumatology Classification Criteria	370
APPENDIX 2: Ethics approval	372
APPENDIX 3: Letter of invitation from Consultant and principle researcher	378
APPENDIX 4: Consent form	379
APPENDIX 5: Letter from principal researcher	380
APPENDIX 6: Information sheet	381
APPENDIX 7: Interview guide 1	383
APPENDIX 8: Interview guide 2	385
APPENDIX 9: Abstract of presentation at WCPT	386
APPENDIX 10 Vignettes of illness narratives	387

## LIST OF FIGURES

<b>Figure Number</b>	<b>Table description</b>	<b>Page</b>
<b>Figure 1</b>	Sample recruitment	<b>127</b>
<b>Figure 2</b>	To demonstrate the position of interviews within this study along the continuum of qualitative interviewing	<b>137</b>
<b>Figure 3</b>	The 'kaleidoscope' of quest, chaos and restitution narratives in individuals with FMS	<b>176</b>

## LIST OF TABLES

<b>Table Number</b>	<b>Table description</b>	<b>Page</b>
<b>Table 1</b>	Summary of qualitative research studies of FMS experience included in review	<b>50</b>
<b>Table 2</b>	Key characteristics of pragmatism as applied to this study	<b>86</b>
<b>Table 3</b>	To demonstrate how rigour has been addressed within this study	<b>118</b>
<b>Table 4</b>	To demonstrate development of coding scheme after first interviews	<b>143</b>
<b>Table 5</b>	Critique of research studies utilising Franks' model of quest, chaos and restitution	<b>156</b>
<b>Table 6</b>	To show dominant narrative, themes and sub-themes within the findings	<b>169</b>
<b>Table 7</b>	Demographic, FMS and interview related information of study participants	<b>171</b>

## LIST OF ABBREVIATIONS

<b>AC</b>	Adaptive copers
<b>ACR</b>	American College of Rheumatology
<b>ARC</b>	Arthritis and Rheumatism Council
<b>CFS</b>	Chronic fatigue syndrome
<b>CNS</b>	Central nervous system
<b>DLA</b>	Disability Living Allowance
<b>DYS</b>	Dysfunctional
<b>FMS</b>	Fibromyalgia syndrome
<b>GP</b>	General Practitioner
<b>ID</b>	Interpersonally distressed
<b>PMP</b>	Pain Management Programme
<b>RCT</b>	Randomised controlled trial



# **CHAPTER 1**

## **INTRODUCTION**

### **1.1 Introduction**

Fibromyalgia Syndrome (FMS) has been described within the medical literature for over 100 years and recognised as a distinct clinical entity since 1970 (Smythe and Moldofsky, 1977). In 1990 diagnostic criteria were developed to support research (Wolfe et al, 1990) yet its diagnosis and management have remained contentious amongst the medical fraternity (Erich, 2003; Hadler, 2003; Goldenberg, 2004) with no treatment successful in providing long term symptom relief. It is recognised as a complex bio-psychosocial disorder that predominantly affects women and is 'a burden to sufferers and the health care system' (Lawson, 2003).

This is a qualitative research study that aims to capture the lived experiences of individuals newly diagnosed with FMS and explore how they change over time. This chapter will: introduce the rationale for the study; describe the genesis of the study; describe my personal influences and background as they relate to the study; define the research question, aims and objectives; provide a summary of the methodological approach taken; and finally provide an overview of the thesis, defining the content of each chapter.

### **1.2 Study relevance**

Fibromyalgia syndrome (FMS) is the second most common syndrome seen in Rheumatology clinics (Marder, 1991). It is a musculoskeletal condition characterised by at least 3 months history of widespread pain and pain in 11 out of 18 tender points (Wolfe et al, 1990). Aetiology, pathogenesis and patho-physiology are unclear but it is hypothesized that the following may all play a role: central and peripheral nervous system sensitization, alterations in the function of pain receptors and pain perception, neuro-endocrine abnormalities, behavioural and psychological factors, and genetic and environmental factors (Shipley, 2010; Clauw, 2009) Epidemiology reports a

prevalence of 3.4% of the female and 0.5% of the male population that increases with age (Wolfe et al, 1995) with comparable prevalence shown in Europe (including the UK) (Branco et al, 2009), North America and South America (White and Harth, 2001). It is, therefore, a condition that globally affects predominantly middle-aged women.

The long-term outlook for these patients is poor: four years following diagnosis 97% of individuals continue to suffer symptoms (Ledingham et al, 1993) and there is no single treatment successful in providing long-term symptom relief (Arnold, 2009; Buskila, 2009). A recent meta-synthesis (Sim and Madden, 2008) highlighted the presence of four broad themes associated with illness experience in FMS. They were: experience of symptoms – pain, describing pain, fatigue and psychological problems; searching for a diagnosis – pre-diagnosis, receiving a diagnosis, post-diagnosis; legitimacy including stigmatization; and coping including re-evaluation of life. The burden of FMS was demonstrated in 2001 by the launch of the All Party Parliamentary Group on Fibromyalgia (Lawson, 2003) with the aim of increasing the awareness of FMS and research into it.

There is currently a paucity of qualitative research studying individuals' perceptions and experiences of being diagnosed and living with FMS in the UK. As a consequence there is an absence of understanding of how such individuals experience being diagnosed, how they make sense of (or understand) what has happened to them, and how they come to terms with the changes to their body's and their lives. In addition, there have been no studies investigating whether or how these issues change over time. Acquisition of this knowledge might assist health care professionals in becoming cognizant of how this syndrome manifests itself in patients and their lives and help inform the delivery of a timely and holistic management approach that meets the needs of patients.

### **1.3 Personal background, influences and beliefs**

Detailing my personal biography is necessary when presenting a study of this nature to highlight my position within the research as the research instrument. My cultural background, personal and professional experiences and beliefs influence the 'lens' through which I see the world and have influenced this study from its inception to data collection and finally analysis and write up. They influenced the research question, method and analysis and critically shaped the interactions and relationships I shared with each of the participants. I will refer to the influence that my researcher position had throughout the study but this will be emphasised in chapters 4 and 5.

I am a white British woman who has lived all of her life within the UK. At the outset of the study I was 36 years old and married. On leaving school I left to study Physiotherapy, gaining a Post-Graduate Diploma in Physiotherapy. I then proceeded to work in both the NHS and Private health care sectors for 11 years specialising, after 3 years, in Musculoskeletal Medicine. I undertook many post-graduate training courses, the majority of which developed my technical skills in diagnosis and condition management. In 1994 I became a post-graduate tutor lecturing nationally and internationally and from the early 1990's was utilised as a physiotherapist by the Welsh and then UK Athletics Teams.

In 1998 I began work as a Physiotherapy lecturer/practitioner. I became increasingly self analytical and reflective as I questioned my own practise and endeavoured to teach evidence based practice to the next generation of therapists. I was conscious of a growing awareness of the 'bio-psychosocial' model of health within physiotherapy and the wider health care arena. Since training I had a belief that successful outcomes of treatment were rarely due to the application of technical skills alone. This understanding was developed further with my involvement in athletics where psychological preparation appeared to play a large part in overall performance, and interaction with the medical team and therapists was frequently part of this. I enjoyed the social interaction with my patients, finding out about their lives and contextualising

their conditions in the light of this. Exploration of the experience of health and illness was a growing area of interest and manifests itself in the research question posed within this thesis.

Clinically I was also increasingly conscious of the perceived reluctance and dissatisfaction amongst a number of my colleagues (medical and allied to medicine) to treat patients who had chronic non-specific conditions. These patients rarely got 'better' and appeared to be considered as a drain on resources. With the advent of 'yellow flags' (Main and C de C Williams, 2002) describing potential psychosocial barriers to improvement an opportunity for therapists to limit or not treat such patients appeared. I was curious as to why this was the case, as I often enjoyed the 'challenge' of treating them and attempting not to 'cure' them but to assist them in learning to live with their conditions. These patients shared similar characteristics to those with FMS, having non-specific musculoskeletal pain for which there was often no clear-cut cause.

In 2000 I completed a Post-Graduate Certificate in Health Services Research. When I initially registered I had little experience in research methods and this was considered an appropriate pre-requisite to help me in deciding how I was going to fulfil the research element of my job. It was a requirement of my lecturer/practitioner post that I perform research with the purpose of attaining a PhD. Physiotherapy predominantly operated within a positivist paradigm and I had had little exposure to naturalist and inductive research methods. The Qualitative Methods module 'opened my eyes' to opportunities to understand how patients experience health care and their illnesses. I began to consider how I could explore this using my growing interest in qualitative methods.

In 2001 I was approached by a colleague (Dr Kaye Freeman) within the Division of Physiotherapy who was aware of my interest in qualitative methods and patient experiences. Dr Freeman had initially been interested in performing a large research study incorporating an exploration of epidemiology in primary care of FMS, with a

qualitative investigation of the experiences of patients (those diagnosed) and non-patients (those with symptoms but not diagnosed). This study did not receive the funding required: she suggested I still consider performing a qualitative study into the experiences of patients who have FMS and over the course of the next year the research proposal was developed.

In December 2002 I registered for MPhil/PhD studies. The initial research proposal and submission to ethics advocated a mixed methods study performed in two phases: Phase 1 would involve qualitative interviews to identify perceptions and experiences of patients which would be utilised to inform a questionnaire; Phase 2 would then be a questionnaire survey to ascertain the presence and nature of these perceptions and experiences in a wider population.

I then became pregnant. I suspended my studies for eight months, whilst I was on maternity leave, and returned with renewed enthusiasm and clarity of thought. Following a return to the existing research literature I came to the conclusion that it was the richness of the illness experience in FMS that I was particularly interested in. I was curious to gain an understanding of how individuals with FMS interpreted their condition and integrated it into their lives. There was limited qualitative research literature surrounding this and at that time no published qualitative studies involving patients with FMS in the UK. I hoped it might be possible to develop a model/explanation that would help clinicians to recognise and understand what it was like to live with FMS. Whilst recognising the limitations of the scope of this study I hoped the findings might support patients and their clinical management. This changed the focus of the study and it became the basis of that which is presented in this thesis. I consider exploration of this phenomenon to demonstrate the importance and originality required for study at PhD level.

Further interruptions in my thesis occurred throughout its duration for both personal and professional reasons. In 2006 the political climate within the local NHS Trust

where I worked created a climate of job uncertainty and I returned to fulltime clinical practice as an extended scope physiotherapy practitioner. I continued my studies albeit on a more part-time nature with only one day for study available in my own and work-time. In 2008 I separated from my husband and divorced in 2010. The consequence of this was an extension, by one year, to the write-up period of my PhD. Further discussion of this will be described throughout the thesis, with respect to the influence this had on the design and conduct of the study. Emphasis will be placed upon how the study evolved and how this was in part caused by the period of data collection within the study and the longevity caused by two periods of suspension.

Throughout this thesis critical reflection will be utilised to demonstrate how my personal and professional knowledge and experience have informed and been considered within this study. This will be highlighted in Chapters 4 and 6.

#### **1.4 Study aims and objectives**

This study aimed to answer the research question: 'What are the experiences of individuals recently diagnosed with fibromyalgia syndrome and do they change over time?'

To answer this question the objectives of the study were:

- To identify and recruit individuals newly diagnosed with FMS by a Rheumatology Consultant in a Secondary Care Setting
- To gain local ethical and R&D approval
- To use semi-structured qualitative interviews to capture the lived experiences of individuals newly diagnosed with FMS
- To explore whether time mediated the experiences of diagnosis and living with FMS through interviews performed at three time points: baseline (within 3 months of diagnosis), at 1 year and 18-24 months)
- To identify what if any meanings could be inferred from their experiences

- To develop a theoretical model to explain the lived experience of individuals with FMS that might facilitate their holistic assessment and management by clinicians

## **1.5 Operational definitions**

For the purposes of this study Fibromyalgia Syndrome (FMS) was defined by the American College of Rheumatology Criteria (Wolfe et al, 1990) which in summary are: 3 month history of widespread pain, in all four quadrants of the body, with pain in 11 of 18 tender point sites on digital palpation (Appendix 1) diagnosed by a Consultant Rheumatologist.

## **1.6 Methodological approach**

Qualitative semi-structured interviews were used to discover the experience of patients newly diagnosed with fibromyalgia by a Consultant Rheumatologist. Interviews were conducted at baseline (within three months of diagnosis), 12 months and 18 -24 months after diagnosis.. This study followed an iterative emergent design (which will be described in detail in Chapter 4) and is evidenced in the movement from iterative thematic analysis to narrative thematic analysis. This was carried out to ensure that the objectives of the study were met using the most appropriate methodological approach and as a result temporal narratives have been produced to explain the findings. The study was influenced by the philosophical perspectives of pragmatism, and the theoretical perspectives of feminist methodological principles and critical reflection.

## **1.7 Overview of the thesis**

This thesis contains 8 chapters including this introductory one. Below I outline the structure of each one.

## **Chapter 2: Literature Review**

This Chapter aims to contextualise the study by providing a review of the theoretical and clinical literature which underpinned the study. Due to the exploratory nature of this study the literature utilised to inform the study has evolved and changed over time. This will be elaborated on within the methods, results and discussion chapters. However, it is important that the initial literature (to the point of commencement of data collection) is discussed in order to justify the development of the research question and subsequent choice of methodological approach taken.

This chapter includes 2 main sections. Section 1 provides an overview of the condition, its diagnosis, epidemiology, prognosis, aetiology and management. It highlights its contested nature and lack of consensus regarding these issues. Section 2 presents a critique of qualitative research studies that have previously investigated the experiences of individuals with FMS. It identifies the key findings from these studies and identifies gaps in the literature that were present at the outset of this study.

## **Chapter 3: Methodology and Epistemology**

This chapter will describe the study design and will place particular emphasis on discussing the theoretical and philosophical perspectives which underpinned the qualitative approach adopted. There are two sections to this chapter. Section 1 considers the epistemological foundations upon which the study was based with specific reference to pragmatism and critical reflection. Section 2 discusses the methodological approach taken, including feminist principles, and the use of a qualitative design to address the aims and objectives of the study. There will be reference to methodological issues in data collection, sampling, ethics, data analysis and rigour.



#### **Chapter 4: The Study Method**

This chapter will describe the methods which were employed to generate the data and subsequent findings from this study, with a focus on research in action. It will describe: the context in which the study took place; the sample design, selection and recruitment; the process by which data collection took place and finally how data analysis was performed. Consistent with qualitative methods this process was iterative and was continually informed by the process of data collection, analysis and critical reflection. As a result the chapter is presented in two stages, the initial design decisions and fieldwork, to highlight how changes in methods were employed to ensure the objectives of the study were met.

#### **Chapter 5: The Results**

This chapter presents the findings of the study. It attempts to provide a rich account of the experience of being diagnosed with and living with FMS. Analysis of the results are presented to demonstrate how individuals with FMS utilise illness narratives consistent with those of quest, chaos and restitution as described by Arthur Frank (1995) to make sense of their illness experience. This study will suggest that individuals with FMS begin with a restitution narrative, then move towards a chaos narrative when their symptoms fail to resolve and they struggle to get diagnosed. Some participants will then remain in chaos whilst others move towards describing a quest narrative. This study will propose that there are 2 types of dominant quest narrative: active engagement and active disengagement. Throughout the study it will be highlighted how the restitution narrative remains in the background with continued hope of a cure. Each narrative preference is not uniform across the stories of the patients but contains common characteristics as it is told through the unique perceptions and experiences of the individual.

#### **Chapter 6: Reflexivity and the Researcher Position**

This chapter presents details of the reflexive analysis that took place within this study and discusses how this was central to evidence gathering, analysis and interpretation.

Emphasis is placed on the researcher position and how the study and its findings are a product of the interaction between the researcher and the researched. Particular reference is made to how this study was influenced by the philosophical assumptions of pragmatism and feminist methodological principles, and the tensions created by the practitioner researcher. This chapter will use also reflexivity to evidence the strengths and limitations of the study.

## **Chapter 7: Discussion and conclusions**

This chapter summarises the findings and aims to explain them further using contextual insights from relevant literature. The findings will be placed in the context of previous literature exploring the experiences of patients with FMS (introducing more contemporaneous literature), as well those studies that have also utilised Frank's illness narrative typologies. It will highlight both the parallels and differences of this study and suggest how the narrative typologies presented are underpinned by issues that include diagnosis, biographical disruption, loss of self, identity and stigma. The clinical relevance of the study will be considered and recommendations for future research made.

### **1.8 Conclusion**

This chapter has presented: the rationale for the study; the research question, aims and objectives; an overview of the methodological approach taken; and an introduction to my position and influences within the study. It has summarised the content of the thesis and highlighted the iterative nature of the study which has allowed the depth of the illness experience of individuals living with FMS to be explored and explained through the development of narratives.

The next chapter will describe the literature that informed the study at its inception.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter aims to contextualise the study by providing a review of the theoretical and clinical literature which underpinned the study. Due to the iterative and emergent nature of this study the literature utilised to inform the study has evolved and changed over time. This will be elaborated on, and additional literature introduced as appropriate, within the methods, results and discussion chapters. It is important however that the initial literature (to the point of commencement of data collection) is discussed in order to justify the development of the research question and subsequent choice of epistemological and methodological approach taken.

This chapter includes 2 main sections. Section 1 provides an overview of the condition including its diagnosis, epidemiology, prognosis, aetiology, management, impact on quality of life and coping. It highlights the contested nature of FMS and lack of consensus regarding these issues. Section 2 presents a critique of qualitative research studies that have previously investigated the experiences of individuals with FMS. It identifies the key findings from these studies and identifies gaps in the literature that were present at the outset of this study.

#### **2.2 Fibromyalgia syndrome: an overview**

##### **2.2.1 The history**

The presence of widespread chronic pain has probably existed for many years. However it is only in the later part of the twentieth century that the term fibromyalgia syndrome (FMS) has been adopted to describe a distinct clinical entity. The term "fibrositis" was first utilised in 1904 to describe lumbago and the associated inflammatory response that was considered to be present within the connective tissues (Gowers, 1904). Throughout the twentieth century a number of authors (Kellgren, 1938 cited in Chaitow, 2001 p.3; Mennell, 1952 cited Chaitow 2001 p.3)

began to recognise the presence of discrete tender points in muscle, ligament, tendon and joint structures which produced both local and referred symptoms. However, at this time there was no standardisation of diagnostic terminology or causation nationally or internationally (Doherty, 1993) and it was often classed as “non-articular rheumatism”.

In the 1970's Symthe and Moldofsky, together with co-workers, demonstrated there was a population of patients with widespread musculoskeletal pain who also exhibited multiple tender points on palpation and a disruption in their sleep (Moldofsky et al, 1975; Smythe and Moldofsky, 1977). In recognition of the absence of any inflammatory component the condition became known as fibromyalgia (Yunnus et al, 1981) and with a clear lack of underpinning pathophysiology the title of fibromyalgia syndrome (FMS) was conferred.

In 1990 the first universally accepted classification criteria for FMS were published (Wolfe et al, 1990) and were commonly adopted as inclusion criteria for research into the condition. Acceptance of these classification criteria has led to an increase in published research and a continued debate over diagnosis, aetiology and management. Although not the original intention the criteria are frequently adopted by Rheumatologists in the process of diagnosis, assisting them in the discrimination between FMS and other chronic musculoskeletal pain disorders (Geenan and Jacobs, 2001).

### **2.2.2 Diagnosis**

The diagnosis of FMS currently occurs within a biomedical paradigm but lacking a diagnostic test and pathological explanation diagnosis is currently criteria based. As a condition it generates conflict and controversy within the medical profession and in the past has been dismissed as being of little medical interest (Doherty, 1993). The bias of the medical profession towards a pathological and structure based model of illness and disease has led many to contest its' existence (Erich, 2003; Hadler, 2003). Time

and the advent of new technology may provide the evidence that the sceptics of this condition require in the same manner that patients with MS were acquitted of their label of 'malingerers' and 'psychologically disturbed' with the development of MRI (White, 2004).

Diagnosis is commonly based on the American College of Rheumatology classification criteria (Appendix 1) established in 1990 initially for research purposes (Wolfe et al, 1990). These criteria were generated from a consensus definition of fibromyalgia formulated by investigators from 20 clinical centres in United States of America and Canada. They have been demonstrated to have high specificity (81.1%) and sensitivity (88.4%) in discriminating fibromyalgia syndrome from other chronic pain conditions (Wolfe et al, 1990). Whilst they have been adopted universally (Docherty, 1993; Adams and Sim, 1998) their use within the clinical setting has been disputed (Wolfe, 2003).

Diagnosis with FMS using the ACR criteria requires the satisfaction of two pain dependent criteria (Wolfe et al, 1990). One is the presence of widespread musculoskeletal pain, of more than 3 months duration, in all four quadrants of the body and in the axial skeleton. The other is pain in 11 of 18 specified tender sites on digital palpation of 4kg. Whilst providing a valuable starting point for recognising a distinct clinical condition that lacks a diagnostic test there are also a number of problems with the definition proffered by the ACR:

- There is a dependence on the condition being static and not showing diurnal or daily variation: if the patient attends on a 'good' day or at a 'good' time they might fail to report the pain when digital pressure is applied to the tender points (Chaitow, 2000)
- A patient might exhibit less than the requisite 11 painful tender points rendering the diagnosis negative
- 11 tender points may be present but not in all four quadrants of the body or in the axial skeleton failing to satisfy the criteria

- Application of the tender point count is subject to human error
- Pain created by palpation can be present in 'healthy' individuals albeit in a different number of sites compared to those with FMS (Wall, 1993)
- Individuals with FMS demonstrate global heightened sensitivity to palpation that is not restricted to the tender point sites (Scudds et al, 1987, 1989)
- It does not include the multitude of other symptoms that patients with FMS often complain of, notably fatigue and sleep disturbances

FMS patients frequently describe a multitude of other symptoms including persistent fatigue, sleep disturbances, stiffness, paraesthesia, irritable bowel syndrome, memory and concentration disturbances and micro-circulatory disturbances such as Raynauds Disease (Adams and Sim, 1998; Richards and Cleare, 2000). The omission of these symptoms has led to clinicians questioning the validity of the ACR criteria (Scuds and Li, 1997). In 1992, two years after the publication of the ACR criteria, a consensus document recommended the addition of a number of other symptoms as a basis for diagnosis (Consensus document, 1992). These included the recognition of persistent fatigue, generalised morning stiffness and non-refreshing sleep in the presentation of patients commonly meeting the criteria. In research trials on FMS these are frequently ignored with the ACR criteria being utilised at their expense.

In 1996 Macfarlane et al attempted to improve the face validity of the ACR criteria in a community based study utilising 172 individuals with chronic widespread pain (CWP). Their proposed criteria divided each limb in to four sections and suggested that patients needed to have pain in the axial skeleton as well as pain in a minimum of two sections of two contra-lateral limbs. The use of the 'Manchester definition of chronic widespread pain' was proposed for use in epidemiological studies and aimed to encapsulate a broader population with true CWP rather than regional pain which it was felt that the ACR criteria promoted. Its' use has failed to have been adopted within the Rheumatology medical fraternity.

The establishment of diagnostic criteria, albeit initially intended only for research, is relatively new. This may reflect the requirement of society to try and validate the illness experience of individuals and the role of the health care and benefits systems in managing them, rather than the presence of a distinct clinical entity. Conflict exists within the medical profession as to the role of diagnosis within the management of patients meeting the criteria for FMS. Some authorities suggest that labelling patients with a diagnosis medicalises a condition that is simply a social construct (Hadler, 2003) and promotes illness behaviour (Hadler, 1996; Solomon and Liang, 1997).

Social constructionism considers disease to be the result of human cognition (Jones, 1994) and promotes the question of why medicine has chosen to conceptualise illness in a particular way. The authorities who contest its' existence (Erich, 2003; Hadler, 2003) do not refute the presence of chronic widespread pain but argue for abolition of the diagnostic label. They believe the diagnostic label to be harmful to both individuals and society and argue that the notion of illness is encouraged when in fact the individual is merely demonstrating an inability to cope with the psychosocial stressors of normal life. It is suggested (Erich, 2003) that it is the presence of the diagnosis that determines whether patients with FMS have the condition, in contrast to conditions with clear pathology e.g RA, where patients will have the disease independent of diagnosis. This argument adheres to the biomedical model of health care and fails to recognise (a) that the absence of disease does not equate to an absence of illness and (b) the role that psychological and social factors play in chronic pain disorders (Engel, 1977; Main and C de C Williams, 2002).

It is suggested (Crofford and Clauw, 2002) that the contested nature of FMS may be the result of "psychological distress on the part of patients, physicians or both". Patients with FMS have often had unsatisfactory relationships with the health care system prior to their consultation with a Rheumatologist and this may increase the likelihood of a negative medical encounter. Furthermore the lack of adherence to the biomedical model 'threatens' the reality within which the medical profession manages

musculoskeletal disorders and creates dissatisfaction. This stance offers support to the argument made by Kuhn (1970 cited in Chalmers, 1999) that 'science' i.e. medicine, operates within dominant paradigms resistant to change and that most research reinforces current orthodoxies.

Those who support the diagnostic labelling of FMS (Goldenberg, 2004; White, 2004; Crofford and Clauw, 2002) argue that there is increasing evidence for the presence of neurophysiological and neuroendocrine abnormalities as well as psychosocial factors and that health care professionals have an obligation to try and alleviate pain and suffering in those presenting to them. The absence of understanding about the mechanisms underlying this condition should not be interpreted as evidence that the condition does not exist. It is acknowledged that the diagnosis is descriptive, largely one of exclusion and does not imply causation. However, once given it provides a framework to approach the management of the patient and validates the illness experience to the patient and their family (Goldenberg, 2004).

The role of Rheumatologists in providing the diagnosis is supported (Crofford and Clauw, 2002) as the condition co-exists, and is influenced by non-biological factors which mediate symptoms, in other conditions presenting to this speciality e.g. RA. These supporters for FMS are demonstrating that the 'clinical gaze' of Rheumatology (Foucault, 1971 cited in Jones 1994) has created a body that is only visible when viewed through the 'anatomical' atlas' and that this is only one way of conceptualising the body. This has inherent weaknesses when addressing criteria based diagnostic conditions such as FMS.

In support of those that advocate diagnosis of FMS as a useful part of managing this condition there is no evidence that labelling patients with fibromyalgia is associated with a worse prognosis or greater health service utilization. White et al (2002) in a prospective within-group study of 72 patients demonstrated that newly diagnosed patients with FMS report fewer symptoms, are more satisfied with their health and



show no increase in disability claims 3 years post diagnosis. The study lacked sufficient power to detect within-group differences and failed to identify whether patients with a label were able to access FMS specific treatment.

The diagnosis of FMS challenges the medical model which is biased towards a pathological explanation of disease. The differentiation between FMS and other syndromes such as chronic fatigue syndrome and myofascial pain syndrome is acknowledged as complex (Adams and Sim, 1998) with overlapping of clinical features. Doctors play a crucial role in the diagnosis of FMS and validation of the illness experience, determining whether individuals will be permitted to enter the 'sick role' (Parsons, 1951). The ongoing debate in the medical literature about diagnosis reinforces the argument that it is the role of doctors to police the sick role and in doing so exercise a function of social control to limit the deviant behaviour manifested in the illness experience of FMS. The level of functional incapacity and psychological distress experienced by patients with FMS may render it more amenable to a bio-psychosocial model of assessment and management (Engel, 1977).

### **2.2.3 Epidemiology**

Fibromyalgia has been identified in all age groups, cultures and ethnic groups but consistent with studies on chronic widespread pain (Gureje et al, 1998) shows an increased prevalence in women and with advancing age (Wolfe et al, 1995).

Difficulties exist in comparing incidence and prevalence between countries and between research studies owing to the inconsistency in approaches to diagnosis and case identification (Schochat et al, 1996; Scuds and Li, 1997; Adams and Sim, 1998). Community based studies frequently use self-report screening questionnaires followed by assessment of those reporting widespread body pain. The reliance on self report threatens the validity of this measure of prevalence (Wolfe et al, 1996) yet there is no alternative measure available to meet the demands of validity and cost of application.

There have been no UK epidemiological studies to assess the prevalence of FMS specifically although a number of studies have been performed to assess the prevalence of chronic widespread pain (Croft et al, 1993). One study performed in the North of England utilised a cross-sectional postal survey of 2034 adults to demonstrate the presence of widespread pain in 11.2% of the population. A follow-up population based survey of 3004 subjects (Hunt et al, 1999) utilising the 'Manchester' definition for CWP showed a population of 4.7%, with a ratio of female: male prevalence of 5.3%:3.7%. Given the widespread lack of adoption of the 'Manchester' criteria in epidemiological studies of FMS these figures cannot be used as prevalence estimates in FMS. However, in the absence of studies utilising the ACR criteria in the UK they do give an insight in to the potential prevalence within the UK.

Community population based studies in the USA (Wolfe et al, 1995) and Canada (White et al, 1999) have both reported similar estimates of prevalence. They identified that 65% of the general population are pain-free, 5% have temporary pain, 20% have regional pain and 10% have widespread pain. Of these 2% meet the ACR criteria for FMS (Wolfe et al, 1990). Prevalence is linked with gender (1.5% are female and 0.5% are male) and age. It is rarely seen in children (Docherty, 1993) and at the ages of 18-30 years the occurrence is 0.9% (Wolfe et al, 1995). Prevalence peaks to 7.4% in women in the 70-79 age group where it is frequently accompanied by other co-morbidities.

Patients with FMS are a burden to the health care system. They have high rates of utilisation of health care services and report more symptoms than patients with other musculoskeletal conditions (Wolfe et al, 1997). In the USA (Marder, 1991) they are the second most common condition seen in Rheumatology Clinics and account for 10-20% of new patients seen in Rheumatology Clinics and 2.1-5.7% of patients seen in Community clinics (Wolfe et al, 1997). These clinic based estimates fail to account for patients with FMS who are seen in pain clinics or mental health specialities, and there is no more up to date information that succeeds this.

Reflecting the higher reported prevalence of FMS in the female population much of the research that is conducted is on women with fibromyalgia. It is possible that the prevalence itself is a result of gender and the established differences in the consumption of health care (Jones, 1994) rather than a true discrimination of the disease. Studies investigating non-patients with these symptoms are lacking and this maintains the position that this is a disease of women. It is also possible that the higher incidence in women influences the experience of patients within the male dominated hierarchy of medicine from assessment and diagnosis to management and research.

#### **2.2.4 Prognosis**

There have been a limited number of studies into the long term outlook for patients with fibromyalgia, with no studies identifying any causal association. The long term prognosis is considered to be poor (Henriksson, 1994; Wolfe et al, 1997) with the majority of patients continuing to suffer symptoms that are unpredictable and varying in severity and their impact on function. The poor prognosis and contestable nature of the illness may influence the perceptions and experiences of sufferers.

A six year prospective study (Baumgartner et al, 2002) suggested that patients with FMS undergo a process of adaptation that is independent of symptom severity. The sample size was small (n=45) and patients had previously participated in a research study of electroacupuncture. 62% patients experienced a statistically significant worsening of their regional pain scores and yet demonstrated a significant improvement in their psychological well-being as measured by self control, general health and vitality.

Similar findings have previously been reported (Kennedy and Felson, 1996). In a ten year prospective study, in the USA 66% of patients reported symptom improvement and 55% had moderate to severe pain and stiffness. 2 patients also committed suicide the contemplation of which has since been demonstrated in a qualitative study

(Bernard et al, 2000). The sample size was small (n=39), nearly ¼ were lost to follow up (n=10) and the original study took place prior to the publication of the ACR criteria for diagnosis threatening consistency in sample selection.

It has been suggested (Wigers, 1996) that positive predictors of outcome include adequate physical activity (more than 30 minutes of exercise 3 or more times per week) and increasing age. In contrast ongoing pain and disability are predicted by receiving a permanent disability pension and more than 2 major life events. This study is limited by small sample size (n=44) and previous participation in an intervention study of exercise and stress management which may have influenced outcome.

In a prospective study (Ledingham et al, 1993) of 72 patients in the UK four years post-diagnosis 85% of patients continued to satisfy the ACR criteria for diagnosis and 97% continued to show high levels of functional disability, anxiety and depression.

20% reported an improvement since diagnosis in contrast to 60% who considered themselves worse off and 50% who had since retired as a result of their symptoms.

There is no evidence that this clinical picture has improved in the UK although studies performed elsewhere (Granges et al, 1994) suggest that long term outlook is not always poor. Limitations of this study are small sample size (n=44) and lack of use of ACR diagnostic criteria. However at 2 years post diagnosis they found 47% of patients in a community setting no longer fulfilled the diagnostic criteria.

The evidence presented supports the premise that the long term outlook for these patients is poor and knowledge of this may influence the illness experience of patients and their perceptions of their diagnosis. Current studies of long term outcomes use patients who have had their symptoms for some time (Simms, 1996) making between case comparison of outcome difficult. There is an absence of research to evaluate how the lived experience of FMS changes over time and how patients perceive their prognosis.

### **2.2.5 Aetiology**

The precise aetiology of FMS remains unclear and this absence of a clear mechanism plays a part in the continuing debate amongst health care professionals as to its existence. It is over sixteen years since Henriksson (1994) stated that the pathogenesis was like "a chain of events, some links are still missing and some links are weak". Whilst this is still the case a growing body of evidence (Desmeules et al, 2003; Staud et al 2003; Staud and Domingo, 2001; Russell, 1998) suggests that the majority of FMS patients may exhibit central pain processing abnormalities and that these may be influenced by genetic and environmental factors.

The possible link between genetic factors and FMS has been suggested from the findings of research studies that have investigated the aggregation of FMS in families (Arnold et al, 2004; Buskila et al, 1996) comparing the presence of FMS in families where a family has FMS or RA. An early family interview study (Buskila et al, 1996) identified a strong aggregation of FMS in families with FMS together with a co-aggregation of FMS with major mood disorders. This study did not use the ACR criteria for diagnosis of FMS instead using assessment of symptoms only. The findings however were supported by a family controlled study (Arnold et al, 2004) that did use the ACR diagnostic criteria for entry in to the study. This proposed that first degree relatives, of patients with FMS, when compared with the general population show an 8-fold increased risk in the likelihood of developing FMS.

Further support for genetic factors being involved in the aetiology of FMS have been demonstrated in studies (Bondy et al, 1999; Offenbaecher et al, 1999; Buskila et al, 2004) that have identified the presence of raised genetic polymorphisms in individuals with FMS. It is postulated that these genetic polymorphisms adversely affect monoamines and/or neuro-modulators that have a strong influence upon the stress response and peripheral and central pain mechanisms. This then predisposes these individuals to the development of FMS.

### 2.2.6 Pathogenesis

The pathogenesis of a condition is the mechanism by which aetiological factors cause a condition or disease, or the step by step development of a condition or disease. The mechanisms that have been linked to the development of FMS have consistently been proposed as related to the role of stressors and neuro-endocrine abnormalities.

Stressors involved in its aetiology are complex and multi-factorial and it is suggested (Pillow et al, 1996) that persistent and ongoing stress that is not a threat to survival may lead to a greater risk of developing FMS than a single major stressful event. For example, it has been suggested infection (Goldenberg, 1996) or trauma (Buskila et al, 1997) may be predisposing factors in the development of FMS. This would support patients' descriptions of a temporal relationship between physical trauma or illness and the onset of their symptoms but there is no conclusive evidence of such a link.

An association with stress related to the work place and abuse has been demonstrated (Kivimaki, 2004). A prospective cohort study (Kivimaki, 2004), of Finnish hospital workers utilised self-report questionnaires (n=4791) to demonstrate a two to four fold increase in the development of FMS, when other covariates of age, obesity, smoking, gender and income were controlled for. Whilst the results should be reported with some caution due to the reliability of self-reporting, the same correlation was not found with other musculoskeletal conditions such as low back pain and arthritis. Also, the findings do not imply causation and may be the result of other confounding variables.

Links with a history of sexual abuse have also been suggested (McBeth et al, 2001; Boisset-Pioro et al, 1995; Alexander et al, 1998; De Civita et al, 2004). Individuals meeting the ACR criteria for FMS are more likely to report the presence of adverse events in childhood, although the only statistically significant predictor of pain in adulthood is hospitalisation (McBeth et al, 2001). Between 53% and 63% of female patients with fibromyalgia self-report sexual or physical abuse (Boisset-Pioro et al, 1995; Alexander et al, 1998; De Civita et al, 2004) and this is higher than control

groups and patients with other musculoskeletal disease. It may be the presence of depression (De Civita et al, 2004), that mediates the association between pain and a history of sexual abuse in childhood or adulthood although this does not explain all of the effect. The reliance on self-reporting threatens the validity of this study and is unable to identify whether the depression precedes or is a result of the development of FMS symptoms.

High “action-proneness” and an associated “overactive lifestyle” have also been implicated (Van Houdenhove et al, 2001) in the development or maintenance of FMS. A validated self-report questionnaire (the HAB), completed by patients (n=62), with FMS and chronic fatigue syndrome (CFS), and their significant others demonstrated high levels of “action-proneness” compared to ‘normals’. With an increased belief that psychosocial factors may have an impact on the aetiology of FMS this finding may lend strength to the argument that it is the result of longstanding and recurrent stress on the individual.

It must also be acknowledged that pain itself is a sensory and emotional experience (Mersey and Bogduk, 1994) as defined by the IASP. The experience of pain is influenced by the perception of pain, and this is influenced by emotional and psychological factors. Whilst at present there is little absolute evidence of explanatory patho-physiological mechanisms research evidence is increasingly demonstrating that this is not a disorder of the mind alone.

Depression, anxiety, poor coping skills and a previous history of traumatic life events have been suggested by some authorities as predisposing factors in the development of FMS whilst others support the stance that “psychological and physiological ill health move in tandem” (White, 2004). One third of patients with FMS report significant psychological distress (Yunnus, 1993) and more stressful life events than those with RA (Uveges et al, 1990; Hassett et al, 2000). Whilst there is no proven association between mood disorder and tender point score ( Okifuji et al, 2000) those patients who

are depressed cope less well with their symptoms; over anxiety and stress exacerbate the symptoms through increased pain perception and muscular tension (Henriksson, 1994).

Neuro-endocrine and neuro-chemical abnormalities have been demonstrated in FMS patients although at present it is not known whether they are in fact aetiological or adaptive responses of the body (Staud and Domingo, 2001). They exhibit abnormalities in function of the hypothalamic pituitary axis (HPA), the sympathoadrenal system, the hypothalamic-pituitary-thyroid axis and the hypothalamic-pituitary growth hormone axis. Normal function of these systems is required for physiological pain modulation and muscle maintenance and repair. HPA dysfunction in patients with FMS may be due to prolonged stress: patients with FMS demonstrate abnormal adrenal response to exercise, analogous to an inability of the autonomic nervous system to respond to stress (Clauw, 1995). Patients with FMS also demonstrate abnormalities in functioning of the autonomic nervous system characterised by an impaired ability to respond to stress. Studies have demonstrated an altered vasomotor response (Bennett et al, 1991) and muscular response (Qiao et al, 1991) to stress, in addition to more recent findings of altered circadian rhythms (Martinez, 1997). The precise nature and role of this dysfunction is unclear.

### **2.2.7 Patho-physiology**

The patho-physiology of a condition relates to the mechanical, chemical and biological changes that occur as a result of a clinical condition, disease or syndrome. A number of pathophysiological changes have been demonstrated in individuals with FMS although the presence of multiple confounding variables can result in difficulties in attributing direct causation. Numerous clinical trials have identified changes in individuals with FMS that encompass abnormalities in muscle, sleep, neurochemicals, and pain and sensory processing.



Early research (Kaylan-Rayman et al, 1984; Yunus et al, 1989) demonstrated that patients with FMS have “moth-eaten” and “ragged red” muscle fibres, a “rubber band” or “taut band” structure, local muscle hypoxia and reduced high energy phosphate levels. However, further research (Simms, 1998; Simms et al 1994) has shown that these findings are not confined to patients with FMS and are more suggestive of de-conditioning.

An initial focus on the role of non-restorative sleep in the development of FMS highlighted that patients with FMS experience an intrusion of their alpha-wave non-rapid eye movement sleep (Moldofsky et al, 1975). Intrusion of this part of the sleep cycle in non-patients, results in the exhibition of similar symptoms i.e. aching, stiffness and presence of tender points. However, these findings lack specificity and are also present in other patients with depression and other chronic pain syndromes (Macfarlane et al, 1996). Whilst a positive correlation has also been demonstrated between sleep quality and pain (Affleck et al, 1996) it is recognised that this may be influenced by the patient's perception of sleep and pain.

Neurochemicals are important in the processing of information at peripheral, spinal and central nervous system levels (Boissevain and McCain, 1991). Serotonin and norepinephrine are inhibitory neurotransmitters mediating activity in the descending inhibitory pathways, thus inhibiting pain. Excitatory neurotransmitters have a role in ‘sensitizing’ the nervous system and thus have pro-nociceptive effects, and include substance P amongst others. Patients with FMS have been shown to have low levels of the precursors to serotonin (L-tryptophan) and its metabolite (5-HAA) in the cerebrospinal fluid (CSF) (Yunus et al, 1992; Houvenagel et al, 1990). However, this is unlikely to provide the complete explanation as utilisation of serotonin based medications and selective serotonin re-uptake inhibitors provides alleviation of symptoms in some patients only. They also show increased levels of substance P (Russell et al, 1993) and decreased levels of norepinephrine (Russell et al, 1992) in the CSF. The clinical relevance of altered levels of these chemical transmitters has yet

to be proven but suggest that individuals with FMS have a heightened sensitivity to pain.

There is a growing body of evidence (Desmeules, et al 2003; Staud et al, 2003; Staud and Domingo, 2001; Russell, 1998) that suggests that FMS is a condition caused, at least partially, by an alteration in the processing of nociceptive stimuli by the central nervous system (CNS). The generalised pain, allodynia (in which pain-free stimuli are perceived as painful) and hyperalgesia (heightened pain response to painful stimuli) would support this hypothesis. Patients with FMS further show abnormal temporal summation of second pain and prolonged after sensations following application of experimental pain stimuli (Staud et al 2001) and a failure to produce analgesia in response to the addition of strenuous exercise in patients with FMS (Vierck et al, cited in Staud et al, 2001). These findings add support to the hypothesis of a central pain processing disorder although at present it is not known whether the condition results as a result of abnormalities in processing in the central nervous system or whether an abnormal input from the periphery produces and maintains central sensitisation (Staud et al, 2003).

Further evidence of heightened pain and sensory processing has emerged with the application of imaging techniques including single photon emission computed tomography (SPECT) and functional magnetic resonance imaging (fMRI). Two studies (Mountz et al, 1995; Kwiatak et al, 2000) utilising SPECT imaging identified decreased regional cerebral blood flow (rCBF) in the thalamus and caudate nucleus, in individuals with fibromyalgia. These findings were further corroborated (Adiguzel et al, 2004) by the finding that rCBF increases in the bilateral thalamus and basal ganglia following the use of amitriptyline in individuals with FMS. This was a small sample but may enhance our understanding of the potential mode of action of amitriptyline for some individuals with FMS.

Combining the aspects of an individual under stress with an increased intrinsic central nervous system sensitivity is the “mature organism model” (MOM) proposed by Gifford (1998). In the MOM model a Darwinian perspective is adopted to describe pain as a “component of the stress response whose prime adaptive purpose is to powerfully motivate the organism to alter behaviour in order to aid recovery and repair” (Gifford, 1999). This model has been proposed, but not proven, for the development of chronic pain rather than specifically for FMS or even CWP. However it may prove useful in helping to understand the interaction of the different body systems in the aetiology, pathogenesis and patho-physiological changes that take place in individuals with FMS.

The literature has demonstrated how individuals with FMS may show evidence of increased activity and the presence of stressful events in their lives. It is possible that to ‘survive’ and maintain homeostasis the CNS, in modulating the body and ‘sampling’ the external environment, becomes increasingly sensitised. This sensitisation may cause the subsequent responses of allodynia and hyperalgesia, together with increased fatigue, for the purpose of ‘protecting’ the individual. Unfortunately over time this may become maladaptive. Knowledge of patients’ experiences in FMS may help in the discovery of potential causation and maintaining factors.

### **2.2.8 Management**

At the inception of the study and commencement of data collection there was an absence of evidence-based guidelines or consensus on the management of FMS. The aetiology was unclear and with a lack of standardised assessment procedures for diagnosis treatment was frequently palliative and lacked standardisation. However, best practice (Goldenberg et al, 2004; Geenan and Jacobs, 2001; Arnold and Keck, 2000) indicated that routine treatment of FMS should encompass the use of pharmacological and non-pharmacological approaches that, in accordance with the heterogenous nature of the condition, are individualised. In general it was considered that management strategies should recognise the differing needs of patients including:

pain severity; other associated symptoms including fatigue; functional impairment; psychological and behavioural impact; and social circumstances/impact.

With the pathogenesis and patho-physiology of FMS unclear there was no medication manufactured specifically for the treatment of FMS. Many of the medicines that are proposed for FMS focus instead on improving the symptoms of FMS i.e. sleep and pain (Richards and Cleare, 2000). Medication trials frequently exhibit flawed methodology with inadequate blinding, small sample sizes and non-standardised outcome measures (Goldenberg et al, 2004). However there was a body of evidence that supported the use of a number of central nervous agents although their efficacy was often only demonstrated in the short-term (6 to 12 weeks). This calls into question their utilisation in the management of a long term condition especially in isolation.

The strongest evidence existed for the use of tricyclic anti-depressants, particularly amitriptyline, whose benefits are thought to be attributed to the ability to prevent the re-uptake of serotonin and possibly norepinephrine, thus modifying pain. Two meta-analyses (Arnold and Keck, 2000; O'Malley et al, 2000) which reviewed the efficacy of anti-depressant treatment on fibromyalgia reported that tricyclic anti-depressants are better than placebo in the treatment of fibromyalgia improving clinical outcomes of sleep, pain, fatigue and overall well-being but having little effect on tender point count. The studies highlighted weaknesses of the RCT's including inadequate blinding, small numbers, the lack of standardised outcome measures and most trials only being of short-term duration (6-12 weeks).

There is moderate evidence for the use of selective serotonin re-uptake inhibitors (Arnold et al, 2002; Goldenberg et al, 1996), tramadol (Russell et al, 2000; Bennett et al, 2003), and pregabalin (Crofford et al, 2002) in the management of FMS with improvements in FIQ scores, pain, fatigue and depression in the short term. There was little or no evidence for the use of any other medications in the management of FMS (Goldenberg et al, 2004; Simms, 1996) 5-HT<sub>3</sub> receptor antagonists (Faber et al,

2000), NMDA receptor antagonists (Clark et al, 2000) and non-steroidal anti-inflammatories (Yunnus et al, 1989).

The evidence base advocated the use of medication that met the individual needs of patients alongside non-pharmacological interventions with best practice most commonly supporting the use of exercise together with cognitive behavioural therapy and/or education. There was limited evidence for any other physiotherapy, complementary or alternative medicine interventions.

CBT adopts the perspective that behavioural responses to illness are influenced by cognitive and affective factors (Johnson, 1997): whether an individual chooses to participate in functional activities will be influenced by the meanings they attach to their symptoms and this may result in more long term improvement in function. Both cognitive and affective components will change over time and research suggests that CBT approaches are more effective when used early on, prior to the development of negative illness behaviours and poor motivation and the adoption of passive coping strategies (Keel et al, 1998).

Strong evidence existed in the literature that education and especially cognitive behavioural therapy (CBT) were equally effective in the management of fibromyalgia (Williams, 2003; Rossy et al, 1999). In contrast to pharmaceutical interventions education and CBT have been shown to produce efficacious results that have lasted up to 6 months (Goldenberg, 1994). 2 systematic reviews (Williams, 2003; Rossy et al, 1999) demonstrated that CBT improves pain, function, fatigue and mood. These reviews recognised that this intervention cannot be blinded and highlighted the benefit that adequate control groups might confer with the use of waiting-list or education groups. These reviews also highlight that patient characteristics might influence outcomes and utilisation of this knowledge should be used when considering the use of psychological interventions.

In the continued absence of clear pathogenesis, opinion (Watson, 2001 in Chaitow) increasingly supports the use of a bio-psychosocial model of multi-disciplinary care. Within this model patient education helps patients to come to terms with the nature of their illness and whilst not eradicating pain assists in the return to function (Masi, 1994). A Cochrane review of this treatment approach found the evidence inconclusive and reinforced by trials of poor methodological quality (Karjalainen et al, 2000). A more recent randomised controlled trial (Oliver et al, 2001) of education versus social support highlighted that patients attending ten weekly two hour sessions of education, followed by 10 monthly education sessions, demonstrated less helplessness. However reliability and validity of the findings are affected by the fact that attendance was as low as 40% at times. This highlights the importance of making such interventions accessible and meaningful to the individuals attending.

Currently there is little evidence within the literature as to what type of information should be provided in education programmes for FMS and what format they should take (Scuds and Li, 1997). There is some consensus that it should include information about the condition, coping strategies, pain management, pacing and stress management (Watson, 2000; Krnisch-Schrwise, 1997). A prospective non-randomised control study (Henriksson et al, 2004) of four educational programmes for FMS (which varied in the duration of the programmes (18-70 hours), personnel involved in delivery and components of education received) found no significant differences between programmes. However, participant self-report of all programmes showed clinically relevant improvements in attitudes towards their illness, their life and ability to control their symptoms. Limitations of the study included differences in the rates of adherence to the interventions (56-93%), small sample sizes and a lack of control group.

An understanding of the perceptions and experiences of individuals with FMS might help highlight the areas where they and their significant others, require education and support to adapt and cope with living with a chronic an unpredictable illness like FMS.

It has been recognised for over 20 years (McCain, 1986) that cardio-vascular exercise is efficacious in the management of FMS with widespread acknowledgement that it decreases symptoms in the short term (Busch et al, 2003; Richards and Scott, 2002; Gowans et al, 1999). Other exercise modalities such as stretching, hydrotherapy and strengthening have been evaluated but the strongest evidence exists for aerobic exercise (Busch et al, 2003). Methodological problems are evident as such studies cannot be blinded adequately and there are problems of adherence (Ciliska, 2003; Richards & Scott, 2002) especially in the long term (McCain et al, 1988). Between study comparisons are hindered by the use of different exercise types, differing intensities, inadequate description of exercise modalities and lack of use of standardised outcome measures.

The exact mechanism for how exercise improves the symptoms of FMS is unclear. However, the rationale for the use of exercise in the management of FMS is underpinned by the knowledge that aerobic fitness is linked with the development of FMS (Moldofsky, 1975) and that FMS patients are de-conditioned (Bennett, 1989) compared to normal "healthy" individuals. It also reflects the cognitive behavioural model where maladaptive fear avoidance behaviour stops individuals from participating in activities they perceive as harmful (Philips, 1987) although the addition of CBT has shown a variable impact on adherence to exercise regimes (Redondo et al, 2004; Gowans et al, 1999; Mannerkopi et al, 2002; Buckhardt et al, 1994).

Physical benefits of exercise are numerous and are reported (Pelligrino, 2001 in Chaitow) to include: decreased pain, improved self-esteem and sense of well being, improved strength and cardiovascular fitness and better sleep (Richards & Scott, 2002; Redondo et al, 2004). Exercise can also confer psychological benefits including improved mental status (Gowans et al, 2001), self-efficacy (Buckhardt et al, 1994) and feelings of well being (Mensghoel, 1992). Exercise is advocated to improve sleep and decrease depression and stress (Royal College of Physicians, 1992) all symptoms experienced by patients with FMS and worthy of evaluation.

In a Cochrane review (Busch et al, 2003) of exercise for treating fibromyalgia syndrome it was concluded that aerobic exercise training improves cardiovascular fitness and tender points. 16 RCT's met the selection criteria for analysis (Busch et al, 2003) although only 13 studies were of moderate to high methodological quality and just 8 met the American College of Sports Medicine guidelines for adequate training stimuli (Busch et al, 2003). Meta-analysis of 4 high quality studies (Busch et al, 2003) found that the aerobic exercise groups showed a greater improvement in aerobic performance (SMD 0.79, 95% CI 0.37 to 1.21) and tender point count (SMD 1.19, CI 0.64 to 1.75), compared to the control groups. Additional evidence was found for strength training with 2 studies demonstrating efficacy in improving pain and function (Hakinnen et al, 2001; Martin et al, 1996). As an alternative to land based aerobic exercise pool based exercise has also been evaluated (Jentoft, 2001) but showed no difference in treatment efficacy in clinical variables of fatigue, stiffness, physical capacity, and measures of well-being, pain and anxiety.

That exercise helps but compliance is poor is a problem that needs to be addressed by researchers and clinicians if its potential role in treatment is to be fulfilled. It is recognised (Watson, 2001 in Chaitow) that adherence is more likely if individuals are engaged in activities that are meaningful to them and can be integrated into their normal daily routine. There is a variable response to the addition of CBT to exercise (Redondo et al, 2004; Gowans et al, 1999; Mannerkopi et al, 2002; Buckhardt et al, 1994) that may reflect a lack of understanding about the meanings that patients attach to exercise. The effect of exercise and education combined has been evaluated over a 12 week period (King et al, 2002): improvements in self-efficacy were seen with a combined intervention of exercise and education compared to education or exercise alone. However, functional improvements in the six-minute walk test were only maintained in the exercise group.

Potential barriers to compliance with any form of exercise could include fear avoidance, disability, pain exacerbation, and difficulties in attending regular exercise



sessions. Little is known about whether exercise is best delivered in health care or non-health care environments (including the patients' home), in groups or individually, supervised or unsupervised. Qualitative research which attempts to identify patients' perceptions, expectations and experiences of living with FMS may help to inform this.

There is at best modest or little evidence to support the use of other therapies in the management of fibromyalgia with the added disadvantage that these interventions promote dependence on therapy and fail to promote self reliance. However with the lack of any evidence for treatment efficacy in the long term increasing numbers of patients are seeking alternative treatments (Kennedy and Felson, 1996; Pioro-Boisset et al, 1996; Bernard et al, 2000). A review (Holdcraft et al, 2003) of complementary and alternative therapy use in fibromyalgia identified 6 types of treatment that are utilised. These included: alternative medical systems i.e. acupuncture and homeopathy; biological based therapies i.e. herbal and nutritional supplements; dietary modifications; energy therapies i.e. magnet therapy; manipulative and body-based systems i.e. chiropractic treatment and massage and; mind-body interventions i.e. relaxation and biofeedback. Although no single treatment was found to be consistently effective, acupuncture demonstrated the highest level of efficacy.

### **2.2.9 Quality of life**

Quality of life is usually rated as low by patients with widespread chronic pain problems and this is no different to patients with FMS. Quality of life in patients with FMS is negatively influenced in a similar way to patients with rheumatoid arthritis (RA) by the symptoms of the condition, the restrictions it places on their life, the impact it has on their relationships with others and economic consequences (Martinez, 1995). However it has also been suggested (Unruh and Henriksson, 2002) that after a process of adaptation some patients with chronic pain will rate their quality of life as high or increased: re-evaluation of their life may allow them the opportunity to develop new meaning which otherwise they would not have achieved.

A survey (Bernard et al, 2000) of 200 FMS support group members in the USA found that quality of life in people with FMS was low. The response rate was low (45%) and men were poorly represented (n=17) but 57% of patients who had previously worked had given up due to their symptoms, and for those remaining in work nearly 60% had reduced their workload. 94% of patients who had experienced marital breakdown cited FMS as the cause and 71% of patients reported a deterioration in their sex lives. Only a small number of patients (n=4) experienced a lack of empathy from others but the majority (n=226) felt that people believed they exaggerated their symptoms. 82% of patients reported onset of depression since the onset of symptoms and over one third had contemplated suicide.

Rehabilitation programmes aim to improve activities in daily living (ADL) and subsequently quality of life of patients. The adoption of adaptation strategies will impact on this and in a questionnaire survey (Lindberg and Iwarsson, 2002) of 34 FMS patients undergoing a rehabilitation programme in Sweden positive correlations between subjective quality of life and perceived activities of daily living were found.

FMS also has an impact on the relatives of sufferers' (Neumann and Buskila, 1997). In a questionnaire survey of 118 relatives of FMS patients and a matched healthy control group of 124, it was found that being related to patients with FMS had a significant deleterious impact on self reported function at work, independence, health and overall quality of life. Results suggest that management strategies should not be isolated to the patient but expanded to include immediate family.

#### **2.2.10 Coping**

Coping has been described "as the process of managing internal and external demands appraised as taxing or exceeding one's resources" (Lazarus and Folkma, 1984 cited Hallberg and Carlsson, 1998 p.310). The experience of pain is mediated by people with chronic pain by a variety of behaviours to reduce the pain itself and its impact on every day life including the subsequent emotional distress.

Coping strategies are the behaviours adopted by individuals and are influenced by their attitudes, beliefs and appraisal of pain. A study of 251 patients undergoing a multi-disciplinary treatment programme (Nielsen and Jensen, 2004) investigated the relationship between changes in treatment outcome and coping, using multi-regression analyses. A correlation was identified between treatment outcome and seven key beliefs and coping strategies, mainly concerned with acceptance of the condition and its symptoms and the use of exercise and pacing. These findings are consistent with other research (Viane et al, 2003) that identified coping in chronic pain, including fibromyalgia, is associated with acceptance of pain, abandonment of a search for a cure and engagement in normal daily activities.

Studies of patients' experiences of living with FMS inevitably describe the processes that patients undergo in learning how to cope with their illness. This process typically begins at diagnosis where the acquisition of a label allows the patient to consider the nature of their illness and how best to manage it (Raymond and Brown, 2000; Schaefer, 1995). As part of this process some of them abandon the traditional medical approaches to care when they fail to alleviate their symptoms and seek home remedies and alternative therapies (Schaefer, 1995; Paulson et al, 2002) often with little effect.

In a quantitative questionnaire survey (Hallberg and Carlsson, 1998) comparing patients with fibromyalgia (n=37) and work related musculoskeletal pain (predominantly low back pain (n=42)) some between group differences were demonstrated in general but not pain specific coping strategies. Both groups predominantly used the general coping strategies of 'substitution', 'social comparison' and cognitive reappraisal' to manage stressful situations in every day life. However they used 'ignoring' and 'distraction' to cope with their pain suggesting the normal repertoire of coping strategies individuals utilise are inadequate to deal with pain.

Self-efficacy is the belief that one can cope competently with a challenging situation (Bandura, 1977) and is related to the development of coping strategies. Individuals with high levels of self-efficacy will adopt coping strategies until success is achieved and high levels of self efficacy have been demonstrated to be predictors of a better treatment outcome in chronic pain patients and fewer pain behaviours in both chronic pain patients and those with FMS (Buckelew et al, 1996; Kores et al, 1990).

A qualitative study (Schaefer, 1997) utilised the completion of diaries over a 3 month period by patients with FMS (n=8) to document how they lived with the condition on a daily basis. Patients recognised that becoming self-aware and the knowledge of symptom patterns, gave them some control over their illness a finding that was previously identified in another study (Schaefer, 1995). They came to realise that maintaining a routine, doing things that were pleasant and appealing, and attending to stress in their life also helped in the management of their symptoms.

For both genders there is a constant negotiation between knowing their limits and wanting to carry out certain activities. The condition imposes a need for the patient with FMS to re-organise their life and either carry out tasks in a modified manner or with the assistance of others. This process of adaptation takes place over time and there are instances when patients will trade the benefits of taking part with the inevitable increase in symptoms they will experience afterwards (Asbring, 2000; Paulson et al, Feb, 2002).

### **2.3 Patient experiences**

Common to all chronic illness experiences fibromyalgia impacts on all aspects of patients lives including their personal relationships, quality of life, self perception, employment status and ability to plan for the future. However, in spite of this and the prevalence of the condition, little is known about what it is like to live this condition, and how this evolves over time from onset of symptoms, to diagnosis and beyond. This is highlighted in the dislocation between the plethora of quantitative research

studies that focus on the biomedical aspects of FMS e.g. aetiology, patho-physiology and 'cure', and the dearth of qualitative studies that explore illness experience.

The main focus of this research study from its inception was to gain an understanding of the illness experience and perceptions of individuals with FMS. This section of the literature review will present the findings of a literature review conducted at the start of the study to identify the evidence base at that time. The objective of this was also to identify literature that would help inform the interview guide, in particular for the initial interviews. Studies were identified through a literature search using the MEDLINE, EMBASE, CINAHL, AMED, BNI AND international bibliography of social sciences databases. Search terms utilised included 'fibromyalgia', 'fibromyalgia syndrome', 'fibrositis', 'qualitative', 'ethnography', 'grounded theory', 'phenomenology', 'interview', 'diagnosis', 'experience', 'illness experience' and 'subjective' were used. Studies were restricted to the English language. 2 studies combined investigation of the illness experience of FMS and CFS. This is a cognate condition but it was recognised that the issues surrounding the nature and meaning of these two conditions might show variation as well as parallels and therefore they were excluded from the literature review.

20 studies were identified whose primary objective was to identify the illness experience of being diagnosed with and/or living with and FMS; they are summarised in table 1. These studies had all involved patients with varying lengths of time since diagnosis and often participating in treatment programmes. The majority were performed at one moment in time. At the time of commencement no studies had been published in the UK, where experiences may be different, and globally no studies had used temporal interviews of patients, failing to acknowledge that chronic illness is an experience that has an uncertain trajectory (Bury, 1991).

These studies have been critiqued and their results highlight a number of key findings regarding the experience of being diagnosed and living with FMS. These are

presented now and where appropriate the findings of other studies are utilised to emphasise their significance or relevance.

**Table 1: Summary of qualitative studies of FMS experience included in review**

<b>Study</b>	<b>Study Method</b>	<b>Sample</b>	<b>Key findings/themes</b>	<b>Limitations</b>
Henriksson, 1995a	Qualitative method  Influenced by ethnography  Semi-structured interviews: occupational case analysis interview and rating scale Transcribed verbatim Content analysis	N=40  Female  N=20 USA; n=20 Sweden (matched for age and duration of symptoms)  ACR criteria for diagnosis  Recruited from out-patient clinics	Encounters  Reactions from others  Family relations  Consequences	Descriptive in nature and  lacks evidence of  development of  theoretical concepts  Poor design flexibility  Lacks evidence of  reflexivity
Henriksson, 1995b	Qualitative method  Influenced by ethnography  Semi-structured interviews: occupational case analysis interview and rating scale Transcribed verbatim Content analysis	N=40  Female  N=20 USA; n=20 Sweden (matched for age and duration of symptoms)  ACR criteria diagnosis  Recruited from out-patient clinics	Routines  Adjustment to changed abilities	Descriptive in nature and  lacks evidence of  development of  theoretical concepts  Poor design flexibility  Lack of evidence of  reflexivity

Schaefer, 1995	<p><i>Qualitative method</i></p> <p>In-depth interviews (n=6 had follow-up interviews)</p> <p>Influenced by Grounded theory and feminist theory</p> <p>Constant comparison method of analysis</p> <p>Interviews tape recorded or analysed from memory</p>	<p><i>Sampled via snowballing</i></p> <p>from community programme.</p> <p>N=36</p> <p>No diagnostic criteria stated</p> <p>Female</p> <p>USA</p>	<p><i>Struggling to maintain a balance</i></p> <p>Searching for a diagnosis</p> <p>Moving on</p>	<p><i>Variation in recording and analysis of data i.e. from audio-tape or memory affects reliability of data</i></p> <p>Use of member checking re: truthfulness fails to establish validity of data</p> <p>Fails to demonstrate theoretical concepts</p> <p>Largely descriptive and at times appears anecdotal with findings not always grounded in the data</p>
Schaefer, 1997	<p><i>Mixed methods</i></p> <p>Health diaries, demographic questionnaire and interviews.</p> <p>Van manen's method of analysis</p>	<p><i>Sampled via snowballing</i></p> <p>from support groups.</p> <p>N=10 recruited (n=8 completed)</p> <p>Diagnostic criteria not</p>	<p><i>Symptoms</i></p> <ul style="list-style-type: none"> <li>• Physical</li> <li>• Mental</li> </ul> <p>Knowing the self</p> <p>Importance of distraction</p>	<p><i>No evidence of validation</i></p> <p>Lack of evidence/adequate demonstration of analysis and emergence of themes</p>



		<p>stated</p> <p>Female</p> <p>USA</p> <p>All pre-menopausal</p>		<p>Fails to demonstrate theoretical development</p>
<p>Kelley and Clifford, 1997</p>	<p>Mixed methods</p> <p>Qualitative ethnographic approach</p> <p>Narrative group sessions and journals</p> <p>Analysed using grounded theory</p>	<p>N=19</p> <p>Female</p> <p>Recruited from out-patient treatment programme</p> <p>Diagnosed by Consultant: not stated if ACR criteria</p> <p>USA</p>	<p>Usefulness of group</p> <p>Changes over time</p> <p>Loss</p> <p>Feeling understood</p> <p>Depression</p> <p>Feeling good</p> <p>Support and empowering experiences</p> <p>Self esteem resources</p>	<p>Sampling strategy and size not justified</p> <p>Little evidence of reflexivity</p> <p>Results largely descriptive</p> <p>Evidence of narrative in data collection rather than analysis</p>
<p>Soderberg et al, 1999</p>	<p>Qualitative method</p> <p>Narrative interviews with focus on life with FM, symptoms, daily life, relationships,</p>	<p>Purposive sample</p> <p>N=14 (n=20 invited)</p> <p>Meet ACR criteria for diagnosis</p>	<p>Loss of freedom</p> <p>Fatigue</p> <p>Living a changed life</p> <p>Economic restrictions</p>	<p>Little evidence of reflexivity</p>

	<p>thoughts and feelings about illness.</p> <p>Transcribed verbatim</p> <p>Phenomenological-hermeneutic method influenced by Ricoeur</p>	<p>Recruited from rheumatology clinic</p> <p>Age 35-50 years</p> <p>Sweden</p>	<p>Threat to integrity</p> <p>Lack of knowledge about FMS and negative attitude of society</p> <p>Seeking explanations</p>	
Hellstrom et al, 1999	<p>Qualitative Phenomenological.</p> <p>Interviews with a focus on 'what it is like to live with fibromyalgia'.</p> <p>Sampled until saturation</p> <p>Interviews transcribed verbatim.</p> <p>Analysed using Karlsson's empirical phenomenological method.</p>	<p>18 patients (n=48 completed questionnaire; n= 20 invited into study)</p> <p>Meet ACR criteria for diagnosis</p> <p>Age 32-55 years.</p> <p>Female.</p> <p>Recruited from 4 local FMS support groups.</p> <p>Sweden</p>	<p>Onset</p> <p>Unpredictable, invisible and incapacitating symptoms</p> <p>Search for confirmation as an ill person</p> <p>Search for a cause of the suffering</p> <p>Demands placed upon oneself</p> <p>Managing experiences of threatening failure</p>	<p>Transferability of findings given sample from self-help group.</p> <p>Questionable true data saturation reached as stopped when next interview repeated</p> <p>No evidence of secondary validation techniques.</p> <p>Findings mainly descriptive with little</p>

			Avoiding thoughts of the future	evidence of theoretical concepts.
Hallberg & Carlsson, 1998	<p>Grounded Theory.</p> <p>Open ended interviews with a focus on 'the womens' experience of the pain and its origin'</p> <p>Transcribed verbatim.</p> <p>Constant comparison method of data analysis.</p>	<p>22 patients: n=14 met ACR criteria for diagnosis; n=8 met Yunnus et al criteria.</p> <p>Age 22-60 years.</p> <p>Female.</p> <p>Sweden</p>	<p>Psychosocial vulnerability:</p> <ul style="list-style-type: none"> <li>• Traumatic life history</li> <li>• Over-compensatory performance</li> <li>• Pessimistic life view</li> <li>• Unsatisfying work situation</li> </ul> <p>Maintaining forces:</p> <ul style="list-style-type: none"> <li>• Professional care</li> <li>• Pain benefits</li> <li>• Family support</li> </ul>	<p>Different criteria for diagnosis utilised affecting transferability and validity of data. Unsure why.</p> <p>Lack of clarity as to whether all patients in-patient/out-patient at time of study affecting transferability.</p> <p>Transferability of findings given patients referred to specialist hospital for assessment for disability pension.</p>

				<p>Good link with existing theory and development of theoretical concepts evident but some invalidated claims/assumptions.</p> <p>Focus on pain dimension may limit validity.</p> <p>No evidence of data saturation being reached.</p>
Mannerkopi et al, 1999	<p>Qualitative method</p> <p>Modified phenomenological hermeneutic method developed by Larlsson.</p> <p>Interviews x 2</p> <p>Transcribed verbatim</p> <p>Recruited from Rheumatology clinic</p>	<p>Purposive sample</p> <p>N=11</p> <p>ACR criteria for diagnosis</p> <p>Female</p>	<p>Struggling</p> <p>Adapting</p> <p>In despair</p> <p>Giving up</p>	<p>Poor evidence of data saturation</p> <p>Identify 4 patterns of living with FMS: ? possible</p> <p>given lack of evidence of saturation and limited sample size</p> <p>Predominantly descriptive</p>

				with little evidence of development of theoretical concepts
Raymond & Brown, 2000	<p>Qualitative method.</p> <p>Semi-structured in-depth interviews: focus on 'experience of having fibromyalgia'</p> <p>Interviews transcribed verbatim.</p> <p>Iterative analysis involving immersion and crystallization.</p> <p>Evidence of researcher validation.</p> <p>Reflexivity used to reduce bias.</p>	<p>N=150 patients from local fibrositis association invited: n=7 interviewed.</p> <p>ACR criteria for diagnosis.</p> <p>Age 38-47 years.</p> <p>Sampling stopped with data saturation.</p> <p>Female.</p> <p>Canada</p>	<p>Continuum of experience:</p> <ul style="list-style-type: none"> <li>• Experiencing symptoms</li> <li>• Seeking a diagnosis</li> <li>• Coping strategies</li> <li>• Accomodating behaviours</li> </ul>	<p>Doesn't define how data saturation recognised.</p> <p>Predominantly descriptive.</p> <p>Little development of theoretic concepts.</p> <p>Uses 'experts' to increase credibility of findings but fails to adequately demonstrate how this is achieved.</p> <p>Fails to adequately demonstrate how reflexivity and attention to individual bias was achieved.</p>

				Narrow age range and members of support group affects transferability.
Hallberg & Carlsson, 2000	<p>Qualitative method.</p> <p>Open-ended interviews; focus on 'experiences of having to live with fibromyalgia'.</p> <p>Interviews transcribed verbatim.</p> <p>Grounded theory.</p> <p>Constant comparison method of data analysis.</p> <p>Allied to study and results presented in Hallberg &amp; Carlsson, 1998.</p>	<p>N=22 from National Insurance Hospital. N=10 in-patients; n=12 out-patients.</p> <p>N=14 met ACR criteria; n=8 met Yunnus et al criteria for diagnosis.</p> <p>Purposeful sampling.</p> <p>Age: 22- 60 years.</p> <p>Female.</p> <p>Sweden</p>	<p>Subjective pain language.</p> <p>Diversified pain coping.</p> <p>Pain communication.</p> <p>Higher order concept: preoccupied with pain.</p>	<p>Transferability affected by sample of chronic patients being assessed for disability pension.</p> <p>Mixed sample of in-patient/out-patients may affect transferability/reliability of data.</p> <p>Unclear why 2 sets of diagnostic criteria used.</p> <p>Largely descriptive in nature.</p> <p>Fails to adequately demonstrate development</p>

				of theoretical concepts although some attempt to link with existing theory.
Soderberg & Lundman, 2001	Qualitative method Phenomenological- hermeneutic method inspired by Ricoeur Narrative interviews	Purposive sample N=50; n=25 FMS and n=25 age matched healthy controls Sweden	Transitions in patterns of daily life Family life Social life Working life Learning to live with changes	Lacked evidence of reflexivity.
Sturge-Jacobs, 2002	Qualitative method Unstructured interviews Phenomenological method Thematic analysis using van- Manen's method	N=9 Female Age 30-56 years USA	Pain the constant presence Fatigue the invisible foe Sleep the impossible dream Thinking of a frog Dealing with a flare up Longing for a normal life The power of naming-	Largely descriptive

			seeking a diagnosis  Living within the  boundaries	
Soderberg et al,  2002	Qualitative method.  Phenomenological-hermeneutic method influenced by Ricoeur.  Narrative interviews with focus on life with FMS and lived experience of tiredness and fatigue.  Transcribed verbatim.  2 phased analysis: naïve understanding and structural analysis.  Aim to compare experiences of healthy women and those with FMS	Purposive sample.  N=50: n=25 FMS and n=25 age matched health controls.  Recruited from rehabilitation centre, n=20 and rheumatology clinic, n=5.  No diagnostic criteria identified  Age: 35-60 years (FMS)  Female.  Sweden	The body as a burden  An absent presence  An interfering obstacle  Being in hope of alleviation	Recruitment from 2  settings unjustified which creates potential to influence validity of findings.  Most women married and educated possibly influencing transferability of findings.  No evidence of critical reflection.  No diagnostic criteria



Paulson, Danielson et al, 2002	<p>Qualitative method</p> <p>Narrative interviews (appeared unstructured) with focus on help given with health care</p> <p>Transcribed verbatim</p> <p>Content analysis</p> <p>Some evidence of secondary validation of analysis</p>	<p>Purposive sample</p> <p>N=19 invited; n=14 recruited</p> <p>ACR criteria for diagnosis</p> <p>Age 41-56 years</p> <p>Male</p> <p>Living with or married to female partner</p> <p>Sweden</p>	<p>Feeling afraid of being looked upon as a whiner</p> <p>Feeling like a guinea pig</p> <p>Feeling hopeful</p> <p>Feeling neglected</p> <p>Feeling no recovery</p>	<p>Related to previous literature but little development of theoretical concepts.</p> <p>Evidence of quotes to demonstrate findings lacking at times e.g. Feeling no recovery.</p> <p>No evidence of reflexivity</p> <p>? transferability given relationship status</p>
<p>Paulson, Norberg et al, 2002</p> <p>(Same sample as Paulson, Danielson et al 2002)</p>	<p>Qualitative method</p> <p>Phenomenological hermeneutic method inspired by Ricoeur.</p> <p>Narrative interviews focus on 'symptoms, daily life, working life, family life and social life'</p>	<p>Purposive sample</p> <p>N=14</p> <p>ACR criteria for diagnosis</p> <p>Age 41-56 years</p> <p>Male</p> <p>Living with or married to female partner</p> <p>Sweden</p>	<p>Experiencing the body as an obstruction</p> <ul style="list-style-type: none"> <li>Living with a reluctant body</li> <li>Living day by day with body in pain</li> </ul> <p>Being a different man</p> <ul style="list-style-type: none"> <li>Not being the</li> </ul>	<p>Transferability affected by relationship status</p> <p>Not clear who analysed data-all or 1 author.</p> <p>Quotations not attributed to individual patients therefore different to formulate nature of</p>

			<p>same man as earlier</p> <ul style="list-style-type: none"> <li>• Not being really understood</li> </ul> <p>Striving to endure</p> <ul style="list-style-type: none"> <li>• Living as normally as possible</li> <li>• Searching for alleviation</li> <li>• Having to nurture hope</li> </ul>	narrative.
Cudney et al, 2002	<p>Qualitative method</p> <p>Telecommunication intervention (computer-based support and intervention project) used. Part of a larger project in which participants engaged on-line in unstructured conversations</p>	<p>Convenience sample.</p> <p>N=10</p> <p>No diagnostic criteria stated.</p> <p>Age 38-55 years</p> <p>Female</p> <p>USA</p>	<p>Pain</p> <p>Fatigue</p> <p>Depression</p> <p>Sleep disturbances</p>	<p>No evidence of secondary validation</p> <p>Largely descriptive</p> <p>No evidence of theoretical development</p> <p>No evidence of reflexivity</p> <p>No evidence of data saturation</p>

	<p>over 5/12 period.</p> <p>Data recorded and dominant themes extracted.</p> <p>Content analysis</p>			
Liedberg & Henriksson, 2002	<p>Qualitative method</p> <p>Semi-structured interviews</p> <p>Data recorded and transcribed verbatim</p> <p>Methods based approach to thematic analysis</p>	<p>N=39</p> <p>Purposive sample: n=19 working; n=20 not working</p> <p>Female</p> <p>ACR criteria for diagnosis</p>	<p>Themes related to factors of importance in work disability:</p> <p>Values and norms</p> <p>Structural factors in society</p> <p>Working conditions</p> <p>Other commitments</p>	<p>Difficulty of recall bias owing to women being out of work for some time.</p> <p>No evidence of reflexivity</p> <p>No evidence of data saturation</p> <p>No evidence of secondary validation</p> <p>Largely descriptive analysis</p>
Thorne et al, 2004	<p>Qualitative method</p> <p>Grounded Theory</p> <p>Semi-structured interviews with</p>	<p>Purposive sample</p> <p>N=11</p> <p>10 Female; 1 male</p>	<p>Process of managing pain</p> <p>Struggle for legitimacy</p> <p>Challenge of sustaining a</p>	<p>No evidence of secondary validation</p> <p>Little evidence of</p>

	<p>focus on 'how do persons with FM describe and explain helpful and unhelpful communications in their health care'</p> <p>Analysis using constant comparison</p>	<p>No diagnostic criteria stated</p> <p>Canada</p>	<p>normal life</p> <p>Helpful and unhelpful communications</p>	<p>reflexivity</p> <p>Lack of diagnostic criteria affects validity of data</p> <p>Infrequent use of quotations to support findings</p> <p>Appears to want to demonstrate that helpful and unhelpful communications are over-riding feature that explains the other themes but there is a lack of clarity in presentation of this.</p>
Wentz et al, 2004	<p>Qualitative method</p> <p>Grounded theory</p> <p>Semi-structured interviews with focus on symptoms, patients</p>	<p>Purposive sampling</p> <p>N=21</p> <p>Age 26-72 years</p> <p>Female</p>	<p>Unprotected self</p> <ul style="list-style-type: none"> <li>Overstrained as a child</li> <li>Unprotected adult</li> </ul>	<p>Transferability may be affected as all women were either working or had worked.</p>

	<p>reflections on illness and herself, life history, lifestyle, activity style and object relations.</p> <p>Transcribed verbatim</p>	<p>ACR criteria for diagnosis</p> <p>Recruited from wide range of clinical settings</p> <p>Sweden</p>	<p>self</p> <p>Compensating strategies</p> <p>Increase in mental load</p> <p>Reduction of cognitive function</p>	<p>Sampling strategy in part influenced by self selection and may influence sample generated</p>
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### **2.3.1 Experiences of being diagnosed**

A number of research studies (Schaefer, 1995; Hellstrom et al, 1999; Sturge-Jacobs, 2002; Throne et al, 2004) highlighted the significant role that being diagnosed had for patients with FMS. Its importance emerged early in the illness experience of FMS when it was felt by patients that symptoms were frequently dismissed or credited with being psychosocial in nature (Hallberg and Carlsson, 1998; Thorne et al, 2004). As a result multiple consultations with a variety of health care professionals were common (Hallberg and Carlsson, 1998; Henriksson, 1995a; Sturge-Jacobs, 2002; Raymond and Brown, 2000) together with a multitude of investigations in an attempt to identify the cause of their suffering. The consultations frequently failed to provide the desired diagnosis and investigations were usually negative (Paulson et al, 2001; Sturge-Jacobs, 2002). As a result patients were often left feeling helpless, anxious and depressed (Henriksson et al, 1995a; Mannerkopi et al, 1999) and frequently sought opinions from other health care professionals e.g. changing doctors or seeking referral to other medical specialists, in an attempt to find someone who was able to provide them with the requisite diagnostic label (Schaefer, 1995).

The majority of patients in studies that highlighted the role of diagnosis, placed emphasis on the need for diagnosis to legitimise their illness experience (Schaefer, 1995; Hellstrom et al, 1999; Raymond and Brown, 2000). There was a strong belief that their symptoms were organic in nature (Hellstrom et al, 1999; Henriksson 1995a) and they appeared to want explanations for their condition that were consistent with a biomedical rather than bio-psychosocial model (Hallberg and Carlsson, 1998). In the absence of diagnosis there was always a concern that doctors had failed to identify the cause of their symptoms and that they had an undiagnosed malignant condition (Hallberg and Carlsson, 1998; Hellstrom et al, 1999; Henriksson, 1995a; Soderberg et al, 1999).

These studies also emphasised the need patients with contested illnesses such as FMS have to be listened to and believed (Soderberg et al, 1999). When this and

diagnosis remained absent they began to question their own credibility and the nature of their illness (Henriksson, 1995a; Schaefer 1995). The provision of a diagnostic label symbolised the end of a journey and was usually received with relief. The relief was attributable to multiple meanings that the label of FMS conferred: labelling provided legitimacy and reassurance that their symptoms were not psychological in origin (Hellstrom et al, 1999; Kelly and Clifford, 1997; Raymond and Brown, 2000; Schaefer, 1995); it provided reassurance that nothing serious was wrong (Henriksson 1995a; Schaefer, 1995; Soderberg et al, 1999); and it provided a meaningful label that could be used to described and validate their symptoms to others (Hallberg and Carlsson, 1998).

Receiving a diagnosis also provided the opportunity to access treatment although they never provided the relief and resolution that had been desired (Soderberg et al, 1999; Soderberg and Norberg, 1995; Hallberg and Carlsson, 1998; Hallberg and Carlsson, 2000). Over time there was the realisation that diagnosis whilst bringing some explanations also brought with it uncertainty, notably about the future and the illness trajectory (Raymond and Brown, 2000).

Previous quantitative studies (Macfarlane et al, 1996b; Bradley, 1998) have identified groups of individuals that experience chronic widespread pain such as fibromyalgia and need a diagnosis versus those that are prepared to continue to live with symptoms and not seek a diagnosis. At the time of this research study there had been no qualitative research studies to explore this and it remains beyond the scope of this study. There have also been no studies that have followed patients following diagnosis to look at how time mediates the meanings attributed to the label or any potential influence this may have on the illness experience for individuals and their process of adaptation.

### **2.3.2 Stigma and illness identity**

The impact on identity and perception of self has been well documented by Charmaz (1983) and Bury (1982) in the context of chronic illness, although not specifically FMS. Individuals with chronic illness are faced with biographical disruption (Bury, 1982) and the inability to participate in activities which they previously utilised to define their concept of self. Over time individuals 'build' new biographies for themselves and with it a new identity (Corbin and Strauss, 1987), although the loss of self is considered (Charmaz, 1987) to cause a powerful source of suffering. These themes will be described further in the next section of the literature review.

The potential for threat to identity and stigma is dependent on the nature of the illness and how it is viewed by society (Scambler, 1991). FMS is a condition that is engulfed by uncertainty regarding its cause and management, and the potential for stigma may be escalated by its prevalence in middle aged women. A number of the qualitative studies on FMS illness experience highlighted the perceived lack of credibility, stigma and threat to their identities they felt, together with the judgements they had to make about how to present themselves to others.

The symptoms of FMS are characterised by their invisible and heterogenous nature that has the potential to influence how they are perceived by others. Externally they can often look 'well' in spite of experiencing symptoms of pain and fatigue (Henriksson, 1995a; Hellstrom et al, 1999; Soderberg et al, 1999). Owing to the fluctuating nature of their illness they can sometimes participate in activities that they are unable to complete on another further occasion adding to difficulties others having in both understanding their condition and conferring them credibility (Hallberg and Carlsson, 1998; Henriksson, 1995a). Individuals as a result often have to endure multiple consultations and investigations prior to being diagnosed. Further threats to credibility are reported with each negative consultation or test result (Thorne et al, 2004; Henriksson, 1995a; Schaefer et al, 1995) and this is compounded by further having to convince their peers that their illness is genuine (Soderberg et al, 1999).



Some studies have also identified the lack of credibility (from health care professionals, colleagues and family) that accompanies diagnosis with a contested condition such as FMS (Sturge-Jacobs, 2002; Henriksson, 1995b). There were contrasting ways in which this was managed. Both Raymond and Brown (2000) and Mannerkopi et al (1999) described how individuals with FMS would fail to disclose their illness identity and endeavour to maintain their previous healthy identities. In contrast Henriksson (1995a) highlighted how disclosure of their illness to others, resulted in their family and peers seeking further information and increasing the support and understanding they were able to give.

Charmaz (1987) has described how people with chronic illness are involved in a constant struggle to maintain definitions of self which are positive and worthwhile which in turn influences their experiences of pain and vice-versa. Similar findings have been reported in FMS (Schaefer, 1997) and describe how self perception was related to the sense of well-being, and self-esteem influences responses and feelings about pain.

Further evidence of the effects of contested conditions on illness and stigma are offered from qualitative research on individuals with both FMS and CFS (Asbring, 2001; Asbring and Narvanen, 2002). These were qualitative interview studies, in Sweden, of women with FMS (n=13) and CFS (n=12), with symptoms of between 1-23 years (average 10 years). With the onset of their illness patients described a disruption in their activity levels and with this a loss of their previous self (Asbring 2001). This was reinforced by a loss or reduction in employment and ensuing social isolation both as a result of financial consequences and being restricted to the home. Over time the majority reconciled themselves to their new lives, rebuilt a new identity and for some this was accompanied by illness gains in which they showed greater appreciation for everyday experiences.

They also identified that they experienced stigma in relation to two aspects of their illness. The invisible nature of the illness made them believe that others, including care givers, work colleagues and employers, and the medical profession questioned their morality a theme closely associated with the stigmatisation process (Goffman, 1963). In conjunction with the absence of physical findings symptoms were psychologised by others which they found "violating" and further increased the burden of the illness. Receipt of a diagnosis helped to re-dress the balance but brought with it the problem of being labelled with an illness which is itself stigmatising. Within these studies all participants were female and no participants were engaged in full-time work which threatens the transferability of the results. The studies have investigated two similar conditions but there is no evidence of searching for any similarities and differences between the two conditions affecting the potential validity of the results. In addition whilst there is an attempt to map the results to concepts of stigma and identity the results are largely descriptive in nature.

As with many chronic illnesses patients with FMS have the potential to experience changes in their identity and stigmatisation. The contestable and unpredictable nature of the illness experience in FMS may reinforce this and it is not known whether experiences elsewhere in the world are also true for patients in the UK or whether re-construction of self is a dynamic process being remodelled throughout the process of adaptation.

### **2.3.3 Experiencing struggle**

Linked to the two previous themes associated with illness experiences in patients with FMS is the concept of 'struggle'. Patients have described (Soderberg, 2000) the "struggle for integrity" owing to the invisible nature of the illness and a lack of understanding from their family, friends and health care professionals. This concept has also been discussed (Schaefer, 1995; Mannerkopi et al, 1999) in the context of a "struggle to maintain balance": a constant process of negotiation exists to manage the symptoms of the illness whilst living a life that is acceptable. For some the struggle is

too great and they relinquish the 'battle' on a temporary or permanent basis. Paulson et al (2002) also highlighted the "struggle for a tolerable existence" reflected in the necessity to achieve balance within the fluctuating phases of the illness.

As discussed in 2.3.1. diagnosis is often a tortuous journey from the onset of symptoms to learning to cope with the illness. Here the 'struggle' is to find a diagnosis and is highlighted in other studies (Asbring and Narvanen, 2002; Paulson et al, Oct 2002; Hellstrom et al, 1998; Schaefer, 1995). The invisible nature of the illness appears to be a barrier in all cultures to receiving an early diagnosis and patients have frequently seen a number of medical practitioners before being diagnosed.

#### **2.3.4 Experiencing symptoms of FMS**

All of the research studies investigating the illness experience of FMS have either alluded to or described in detail the symptoms of FMS. This has been in the context of their nature and how they are experienced and interpreted as well as the effects that they have on the lives of individuals. Pain is the most commonly discussed symptom reflecting the diagnostic criteria (Wolfe et al, 1990) that are most commonly used. Fatigue is also described together with less commonly reported symptoms such as psychological and cognitive dysfunction. What distinguishes all of these symptoms is their invisible, heterogenous and fluctuating nature and this appears to have a significant role in their experience.

As highlighted patients with FMS, by the nature of their condition, experience chronic widespread musculoskeletal pain but quantitative measures of this and tender point counts fail to represent all aspects of the experience. Patients have been shown (Raymond and Brown, 2000; Paulson et al, 2001; Hallberg and Carlsson, 2000) to describe pain that is: local and widespread; that fluctuates; and that is chronic and severe. Patients have been shown to correlate their pain with precipitating events (Raymond and Brown, 2000; Hellstrom et al, 1999) and perceive the origin of it to be within a biomedical paradigm (Hallberg and Carlsson, 2000).

The pain that is experienced has been highlighted as causing contradicting levels of concern dependent on its impact on function (Paulson et al, 2001; Paulson et al, 2002). The effect of the pain can be described as both physical and psychological (Paulson et al, 2001; Paulson et al, 2002; Schaefer, 1997; Soderberg et al, 2002) and can lead to contrasting feelings of being and appearing both ill and well simultaneously (Hallberg and Carlsson, 1998; Schaefer, 1995). Some studies found that participants became able to make causal associations between their worsening pain and, for example, the weather or over-exertion (Cudney et al, 2002; Raymond and Brown, 2000) but were still unable to control it. A number of studies have also suggested a recognition by sufferers' of a link between their symptoms and stress (Raymond and Brown, 2000; Hallberg and Carlsson, 2000), although they strongly rejected the notion that FMS is of psychological disorder (Hellstrom et al, 1999; Asbring and Narvanen, 2002).

A few studies have also reported on the language that patients with FMS use to describe their pain. Consistent amongst all studies is the difficulty that patients frequently have in enabling others to understand their pain experience and once more this was heightened by its invisible and variable nature (Hellstrom et al, 1999; Raymond and Brown, 2000). Metaphorical language is frequently used to try and portray the nature and intensity of their symptoms (Cudney et al, 2002; Hallberg and Carlsson, 2000) including descriptions of 'burning', 'stabbing' and 'aching'. A gender difference has been suggested (Paulson et al, 2000) with the recognition that men will utilise swear words and more aggressive metaphorical language to reinforce their descriptions of pain. They have also been reported (Paulson et al, 2002) as enduring pain for a long time before seeking help, continuing to work sometimes to the point of collapse, because they did not want to be perceived as a 'complainer'.

Patients also commonly experience fatigue, the mechanisms of which are not currently fully understood. When described this is often considered more debilitating than other symptoms and is deemed to compound and be compounded by other

symptoms that are experienced (Cudney et al, 2002; Sturge- Jacobs, 2002). Once more the effects of pain and difficulty in communicating them are negatively affected by their invisible nature. Soderberg et al (2002) highlighted the different ways in which tiredness and fatigue are reinterpreted and experienced by patients with FMS and healthy subjects. Patients with FMS experience fatigue as "a changed experience of a lived body" with the notion of permanence attached to it. In contrast, the experience of healthy subjects suggests that tiredness is a temporary state which will improve with rest. Fatigue infiltrates many dimensions of patients lives including their sleep (Paulson et al, 2001; Paulson et al, 2002), their relationships, routines and physical capabilities (Soderberg et al, 2002; Sturge-Jacobs, 2002). Knowledge of this is important for health care staff if they are to appreciate the burden of unrelenting fatigue experienced by FMS patients when implementing management strategies.

Individuals with FMS have also report other symptoms including depression, sleep disturbances and concentration difficulties (Cudney et al, 2002; Kelley and Clifford, 1997). It has been suggested (Bennett and McCain, 1995) that 45% of individuals with FMS experience major depression within their lifetime. This appears to multi-factorial in nature and possibly related to the nature of their symptoms as well as the psychological distress that the condition causes (Cudney et al, 20002; Kelley and Clifford, 1997). This has parallels with the sleep disturbances that are frequently described; sleep was frequently non-restorative which led to increased pain, fatigue and psychological distress which further exacerbated poor sleep patterns (Cudney et al, 2002; Paulson et al, 2001; Paulson et al, 2002). It similarly reflected the experience of decreasing cognitive function including memory and decision making (Sturge-Jacobs, 2002).

An understanding of the multi-factorial and inter-dependent nature of the symptoms of FMS is important for those treating patients with this condition. With knowledge and appreciation of this management strategies can be more effectively implemented to assist patients living with FMS.

### **2.3.5 Coping and the process of adaptation**

Coping and the process of adapting to life with FMS has been reported in a number of studies investigating illness experience in patients with FMS. Consistent with previous research on chronic pain (Miles et al, 2005) patients experience constraint in their lives in three dimensions: bodily, activity and identity. Integrating this into their lives is central to their process of coping and adaptation and this is demonstrated in a number of ways.

Being diagnosed gave patients access to information about their condition; resourcing and engaging with this material was considered essential by some in gaining understanding and control over their condition (Raymond and Brown, 2000; Soderberg et al, 1999). This information was either used in isolation or together with additional resources such as support groups (Raymond and Brown, 2000) or professional consultations (Hallberg and Carlsson, 1998). All sources of information were integrated and used to develop greater self knowledge about the condition and their body and how best to adapt and cope with the effects of the illness.

In learning to live with their symptoms and incorporate them in to every day life patients adopted a variety of approaches. Many of them utilised pacing (Cudney et al, 2002; Hallberg and Carlsson, 2000; Henriksson, 1995b); some were able to maintain their normal activities albeit with modifications (Hallberg and Carlsson, 1998; Henriksson, 1995b; Raymond and Brown, 2000; Schaefer, 1997) whilst others had to severely restrict their activities (Henriksson, 1995b; Paulson et al, 2001; Mannerkopi et al, 1999). Some of these patients (Mannerkopi et al, 1999) highlighted how they were overwhelmed by their symptoms or life with FMS and as a result withdrew from life unable to cope. This was in contrast to a strategy adopted by a number of patients (Henriksson, 1995b; Mannerkopi et al, 1999) which was to attempt to ignore the pain and continue with life as normal.

The process of adapting to life with FMS was invariably impacted upon by the uncertain illness trajectory that accompanied diagnosis (Raymond and Brown, 2000). Over time the use of pacing and planning of activities enabled a degree of control to be regained over their condition and their lives (Schaefer, 1995; Raymond and Brown, 2000). This could only be achieved with an understanding of what their bodies were capable of and organising their routines accordingly (Asbring, 2001). In doing this their bodies were 'saved' for more important or enjoyable activities. However, there was a growing need to consider that they might need to adjust their plans if, in spite of their best plans and intentions they were having a 'bad day' (Schaefer, 1995).

When considering the needs of patients with FMS it is necessary to consider the styles of coping that they have a natural predilection for. In order for patients to adapt to living with FMS management strategies may need to be engaged that are at odds with those they would normally employ.

### **2.3.6 Experiences of employment**

The symptoms of fibromyalgia often impede the ability of sufferers to remain at work and as such present a cost to both the individual and society. In a UK prospective longitudinal study of 72 patients 50% had discontinued working as a result of their illness, four years following diagnosis (Ledingham et al, 1993) yet patients with FMS often wish to remain or return to the workplace (Liedberg and Henriksson, 2002).

It is not known whether employment has a protective effect in FMS or whether it is a measure of symptom severity i.e. patients with less severe symptoms are able to remain in work. An American telephone survey of 287 female FMS patients (Reisine et al, 2003) reported patients who were employed had better health status in the dimensions of pain, fatigue and function than those who were not employed. This study recognised the role that the demands of family and work place on health status and that this may be a confounding variable that warrants further attention.

Qualitative research studies have reported the difficulties that patients with FMS experience remaining or engaging with work and highlighted that work disability is influenced by both individual and societal factors (Liedberg and Henriksson, 2002; Paulson, Danielson and Soderberg, 2002; Paulson, Norberg and Danielson, 2002). These studies on women (Liedberg and Hneriksson, 2002) and men (Paulson, Danielson and Soderberg, 2002; Paulson, Norberg and Danielson, 2002) have demonstrated that in both genders there is the feeling that the invisible nature of the illness impedes real understanding by colleagues and contributes to feelings of social isolation and stigmatisation in the workplace.

Liedberg and Henriksson (2002) found that remaining in work was important to the women they interviewed in maintaining identity and self esteem, providing a daily routine and maintaining social contact and support. The ability to do so is influenced by the limitations of the individual and their responsibilities outside the work place but also the ability of the work environment to adapt to the individuals capacity through altered working conditions, flexibility and psychosocial support. Consistent with women with FMS, men with fibromyalgia also place a high level of importance on being able to remain in work (Paulson, Norberg and Danielson, 2002) and will push themselves to levels of near collapse in order to do so. A struggle men has been described (Paulson, Danielson and Soderberg, 2002; Paulson, Norberg and Danielson, 2002) to remain in, or return to, work. These authors also reported the process of adaptation that they needed to undergo if they were to cope with their symptoms in a constructive manner. This required the renegotiation of values and "seeing the world with "new eyes"" (Paulson, Danielson and Soderberg, 2002 p.247).

In contrast to women with FMS (Liedberg and Henriksson, 2002) the financial situation was a particular cause of anxiety in men (Paulson et al, Feb 2002) when they were unable to remain in work.

Understanding how FMS impacts on a patients' ability to remain in employment or become employed is important if we are to encourage individuals to reach their



potential and understand what support mechanisms and/or management strategies might be required.

### **2.3.7 Relationships and the experience of FMS**

Chronic illness has been shown (Ohman and Soderberg, 2004; Smith and Friedmann, 1999) to have an impact on the lives of sufferers as well as the lives of those around them. Qualitative studies with FMS patients (Paulson et al, 2003; Soderberg et al, 2003) have demonstrated the impact that fibromyalgia has on relationships, and in particular with the spouse, who is expected to be the primary carer (Weiss and Kern, 1995). At times this can lead to relationship breakdown (Asbring, 2001) as all parties have to renegotiate their new roles. Currently there is no research investigating the impact that FMS has on relationships over time. Utilisation of this knowledge is important in health care planning and in delivery of information and support services not just to the patient but to others affected by the onset of this chronic and unpredictable disease.

Research studies have explored the impact of FMS on relationships through interviewing both male (Soderberg et al, 2003) and female partners of those with FMS (Paulson et al, 2003). Soderberg et al (2003) interviewed 5 men who were married to partners with FMS and identified: the husband's responsibility in the family changed and workload increased in the home; there was a deterioration in intimate relationships although the men reported a strengthening of the relationships with the spouse and the children; there was a negative impact on their social life and the husband had to act as an advocate in the absence of physical signs of illness. Methodological flaws of the study include a small sample size (n=5) and recruitment being through self selection.

A further Swedish qualitative interview study (Paulson et al, 2003) investigated the female partners of men with FMS and highlighted the reluctance of men to communicate about their pain. The women felt excluded and this resulted in feelings

of loneliness enhanced by the increased burden of responsibility in the house and family. Unlike the men interviewed in the previous study the women did not comment on the change in their physical relationships with their partners reflecting a potential gender difference in illness impact. Generalisability of the findings is affected by the young age of the respondents (age 35 to 54 years) and their being well-educated.

Chronic pain has been shown (Smith and Friedmann, 1999) to impact on family dynamics creating feelings of isolation of the individual, a strong sense of togetherness within the family but isolation of the family unit within the community. Consistent amongst the relatives of people living with chronic illness and FMS is a desire to understand the illness and the impact it has. However they experience a lack of knowledge and information (Ohman and Soderberg, 2004; Soderberg et al, 2003; Paulson et al, 2003) from health care staff and this is consistent across both genders. In a study (Ohman and Soderber, 2004) of chronic illness, which included patients with musculoskeletal conditions, partners gained their most important knowledge from others in the same situation. This aspect of information sharing is rarely offered within the management of FMS but may occur through engaging with local Fibromyalgia Support Groups. There is no evidence to establish whether this does occur.

## **2.4 Conclusion**

This literature review has demonstrated how the majority of research into fibromyalgia (at the outset of this study) existed within the quantitative paradigm and that this treats patients as "objects" in contrast to a humanist and qualitative approach to treat them as "subjects" (Jones, 1994). There was and remains a growing body of evidence that FMS is a heterogenous disorder, underpinned by a central nervous system sensitisation. Accordingly it should be assessed and managed using a bio-psychosocial model of health.

This literature review has identified a number of gaps in the literature in defining what it is like to live with FMS. At the time of commencement of this study no published

work in the UK had been identified to identify the perceptions and experiences of patients with FMS. There was no literature available to demonstrate whether the experiences of patients with FMS change over time. Additionally published studies investigated individuals that had been diagnosed with FMS for varying periods of time (< 1 year to > 30 years) and were frequently reliant on recall to describe events that might have happened many years ago. Consistent with other chronic illnesses patients with FMS, and their families, experience a threat to themselves and their social existence and this needs to be understood if assessment and management approaches are to meet their needs. This study aims to address this gap.

## **CHAPTER 3**

### **METHODOLOGY AND EPISTEMOLOGY**

#### **3.1 Introduction**

The literature review identified how, at the commencement of this study, the assessment, diagnosis and management of fibromyalgia were primarily centred within a biomedical paradigm. The review of experiences of patients living with FMS highlighted the need for further research and in particular studies investigating this phenomenon in the UK with patients recently diagnosed. Key themes that might influence these experiences and perceptions were identified in the literature. These included: diagnosis, stigma and illness identity, symptoms, struggle, coping and adaptation, employment and relationships. It was evident that the results of existing studies in Europe, North America and America could not be directly inferred to the UK and that many of these studies had produced predominantly descriptive results. It has been argued (Green et al, 2007) that the movement from description to explanation and interpretation of qualitative research findings has the potential to produce stronger evidence that can increase the generalisability of findings.

Consideration of the aims and objectives of a research study are of paramount importance in determining the research design and methods to be utilised (Bowling, 1999). The research question posed by this study was 'what are the experiences of individuals newly diagnosed with FMS and do they change over time?' In order to answer this, the main objectives were:

- to capture the lived experiences of individuals newly diagnosed with FMS
- to explore whether time mediated the experiences of diagnosis and living with FMS
- to identify what if any meanings could be inferred from their experiences

- to develop a theoretical model to explain the lived experience of individuals with FMS that might facilitate their holistic assessment and management by clinicians

In this thesis I endorse the notion that epistemology, methodology and study methods are irrevocably linked (Carter and Little, 2007) and that their presence should be visible to help establish the rigour of a study. This chapter begins by defining what is meant by epistemology, methodology and method. This is then developed throughout the study to demonstrate the epistemological position of this thesis and the methodological stance taken. The following Chapter 4 will describe the study methods as they were implemented i.e. the fieldwork.

### **3.2 Epistemology, Methodology and Study Methods**

It has been suggested (Carter and Little, 2007) that attendance to the concepts of epistemology, methodology and study method is essential in the performance of qualitative research that is able to demonstrate rigor. Epistemology is considered the theory of knowledge and as a result is concerned with philosophical perspectives associated with how knowledge is generated and justified (Carter and Little, 2007). Methodology pertains to the strategy of enquiry that is adopted and as a result reflects the epistemological assumptions of the study. The study methods are the practical application of the research process that produces the desired knowledge and thus themselves show epistemic qualities.

Within the paradigm of qualitative research it is acknowledged that there are different traditions or 'school's' each associated with a defining ontological, epistemological and methodological commitment to the establishment of knowledge and 'truth'. Qualitative research is recognised as being distinguished from quantitative research by its use of "theoretical plurality" (Hansen, 2006 p.15). Theory from disciplines such as sociology, anthropology, education and philosophy are commonly used as a framework for the study conduct, analysis and dissemination of research (Cresswell, 2003). A number of

qualitative approaches are commonly referred to in both research studies and methodological texts and include grounded theory, phenomenology, hermeneutics and ethnography. Whilst they vary their theoretical underpinnings are united in their belief that: reality is socially constructed; research is an interactive process between the researcher and the subjects; and the findings represent a version of reality that is contextually situated rather than truth (Mays and Pope, 2000).

The literature review has demonstrated how previous research studies investigating illness experience in FMS had utilised different theoretical perspectives including: grounded theory, phenomenology and hermeneutics. When considering the design of this study I was aware that having a theoretical perspective was important and that this perspective had to address: the question I wanted to answer, my motivation for doing the study and the likely audience for the results when it was completed (Hansen, 2006). This is reflected in the statement by McElroy and Townsend (1999, p.64) that "A theory provides a framework for explaining the way social forces work, for answering the question, 'Why?' Because we cannot study everything, the theory we choose determines what problems we will give priority to study, what direction we will consider most profitable to look for answers, and what kind of data we will decide to collect."

I hoped to gain an insight into what it is like to live with FMS and this was influenced by the belief (established from the literature and my experience) that this patient group were poorly managed and understood. It was my intention to develop a theoretical model that would help other health care professionals to understand the illness experience of patients with FMS. This knowledge might inform the management of this patient group and make it a more satisfactory experience for all concerned. It was imperative that the results of the study were accessible and meaningful to these stakeholders and I was conscious of the apparent lack of qualitative research within the medical and physiotherapy evidence base. The techniques and procedures

utilised thus needed to also be considered in the context of how they were performed, presented and the language used to describe the findings.

At the outset of the study I did not have a commitment to a particular theoretical framework but preferred to adopt a pragmatic approach to considering how I could best answer the research question I had posed. The ontological position that I had adopted was that I was interested in understanding the experiences of individuals newly diagnosed with FMS and discovering whether these are mediated by time. Gaining an understanding of the 'world' presented by individuals with FMS might enable me to access social perspectives that they might not be aware of and explain them using both existing and emerging theoretical perspectives.

It is now my intention to describe the theoretical and philosophical perspectives that determined the epistemological position of this study and the methodological approach taken.

### **3.2.1 Epistemology**

Epistemology is the theory of knowledge and is concerned with how we view truth and beliefs or meaning. It is suggested (Carter and Little, 2007 p.1325) that the epistemological position a researcher adopts is influenced by "the discipline the researcher comes from and the formal theories of knowledge the researcher has read" and in its simplest form is concerned with how we justify knowledge. At a number of stages of this study it was necessary to consider the epistemological stance that I was going to adopt if I was going to be able to satisfactorily address the research question that I had posed and produce evidence that was credible.

It is considered (Avis, 2003) common place for qualitative research to adopt an epistemological position that is based on the rejection of a positivist epistemology. Quantitative research and the methods of enquiry associated with it are founded on a theory of knowledge that places emphasis on the empirical scientific method. Its

epistemological stance is underpinned by the philosophical perspective of verificationism which considers the production of knowledge to be dependant on adherence to a system of rules. These rules are associated with systematic, quantifiable, reproducible and objective methods of enquiry that produces evidence based on confirmation of the senses (Avis, 2003).

As demonstrated by the literature review surrounding the experiences of patients with FMS, the questions posed by qualitative researchers in health care were frequently concerned with understanding individuals' accounts of social life and gaining an insight into social behaviour. It is not possible to address these types of research questions utilising research that is fixed, ordered, inflexible and measurement driven. Qualitative research is usually associated with methods of enquiry that are flexible, utilise textual data, involve social interaction between the researcher and subjects, and use methods that are embedded in naturalism.

It has been suggested that "qualitative researchers often feel a particular commitment to a particular theoretical framework and conduct the majority of research within it" (Hansen, 2006 p.16). There are many traditions or methods of qualitative enquiry that are justified as being an appropriate mechanism for generating knowledge. Extending this argument it is my opinion that, when reporting qualitative research, credibility and validity for the strength of arguments are at times based statements that a particular tradition of enquiry was adopted rather than providing adequate evidence of *how* knowledge and beliefs were constructed. In stating this I am not advocating that validity is concerned with process. I would nonetheless share some allegiance with Green et al (2007) who highlights how frequently the reporting of the analysis of qualitative research is poorly described. In order to be able to adequately evaluate the knowledge produced and claims made by qualitative research I would concur with Avis (1995) that qualitative researchers should adopt an approach of presenting "a series of logical arguments" that can be critiqued. This should commence with the research question posed and permeate all aspects of the study



from the methodological approach chosen, to the methods employed, how analysis was performed, and conclusions drawn.

As I developed the research question and the study design, I was aware of a growing tension in my own commitment to utilising a specific qualitative tradition. Given my background as a physiotherapist with little prior knowledge or experience of philosophy, I believed myself to be removed from an allegiance with specific qualitative schools of thought. Through research training (Philosophy of Social Science and Qualitative Research modules) and methodological literature I was exposed to the different approaches that were available to me. However, my positivist background continued to question 'what is the best way to establish the truth?' and 'how will I know what I have discovered is the truth?'

Over time I realised that given the nature of the research question i.e. to uncover experiences of patients, I was most concerned with eliciting not the 'absolute truth' but the truth that individuals wanted to present to the outside world. As a result I came to the conclusion that it was possible for there to be multiple versions of truth and this provided one of the main foundations for my epistemological beliefs. This coincided with the conviction that the research study would be a product of the interaction between myself as a researcher and the participants who engaged in my study.

Alongside this I concluded that if I were to accord credibility and validity to the version of knowledge and truth that I presented (both within and as a result of my research study) I would need to be able to provide an adequate level of justification. In order to do this I would need to adopt an epistemological stance that demonstrated transparency not just in the decisions that were made about methodology and study method but most importantly in the acknowledgement that "it is our own interactions with the world that cause us to have certain beliefs" (Avis, 2003 p.1000). From my position as a practitioner I was conscious that all facets of this research study had the potential to be influenced by own system of beliefs. It was not my intention to provide

a purely descriptive account of the experiences that individuals chose to share with me but to provide a theoretical model to explain them. In order to achieve this I would not only need to conceptualise the evidence generated but critique and develop this alongside existing social theory.

I determined that the adoption of a pragmatic epistemology would best enable me to produce a thesis that answered by research question. Many of the core characteristics of pragmatism appeared to coincide with my own assumptions about truth, knowledge and belief. My epistemological stance was also informed by the principles underpinning critical reflection. In this next section I will attempt to identify a number of these core characteristics and contextualise them within my own researcher position, the research question and the research study.

### **3.2.1.1 Pragmatism**

Pragmatism as a philosophical movement is considered to have been founded in America in the late nineteenth century. It is considered to have its origins in the work of the classic pragmatists Charles Saunders Peirce, William James and John Dewey although this was later expounded by the contemporary pragmatists that included Richard Rorty and Donald Davidson (Hesook and Sjostrom, 2005; Corbin and Strauss, 2008). Pragmatism is not a single philosophical approach but represents a range of positions concerning the nature of knowledge and truth and how these are reconciled within the domains of science and practical life (Hesook and Sjostrom, 2005). Reading about pragmatism led me to the conclusion that as a philosophical perspective it reflected a layering of the work of the different pragmatists and that embedded within it is the notion that the pursuit of, and belief in, absolute truth is futile. Truth as it exists is not fixed but an entity that should be considered transient, conditional and open to development.

The key characteristics of pragmatism as they were applied to this study are detailed in table 2. These characteristics will be discussed throughout this section.

Key characteristics of pragmatism as applied to this study
<ul style="list-style-type: none"> <li>• Establishes the research question as the prime consideration in considering what and how to conduct a research investigation</li> <li>• Rejects philosophical dogmatism and values philosophical dualisms that consider how best to address the aims and objectives of a research study</li> <li>• Considers knowledge as both constructed and founded on the reality of the world that is experienced and lived in</li> <li>• Values the natural world of human experience that incorporates language, culture, societal influences and subjective thought</li> <li>• The application of the Principal of Charity is extended to participants i.e. the belief that truth is obtained through the interaction and disclosure of experience by participants</li> <li>• There might be more than one truth, but some might be more true than others</li> <li>• Advocates fallibilism and acknowledges that knowledge, truth and meaning may be transient and subject to modification over time.</li> <li>• Places emphasis on the development of practical theory and the practical effects that findings may have on e.g. clinical practice</li> </ul>

**Table 2 Key characteristics of pragmatism as applied to this study**

The classic pragmatists rejected positivism and the 'scientific method' and emphasised the importance of considering the value of understanding the human experience. Their philosophical stance and the theories of truth proposed were based in part on the 'pragmatic maxim' attributed to Peirce in 1878 (cited in Putnam, 1995 p.291) which stated: "Consider what effects, that might conceivably have practical bearing, we conceive the object of our conception to have. Then our conception of these effects is the whole of our conception of the object". The implication from this is if there are a number of different conceptions yet the outcome or effects of these

conceptions show no discernible differences, then there can be no disparity between the different conceptions.

From previous research literature and my own experience I was aware that there may be a number of different conceptions associated with the experience of living with a contested illness such as FMS. In order to be able to access the participants' perspective of this experience I felt that it was important to be able to consider all these possible conceptualisations prior to developing my own theoretical model. If all of the different conceptualisations led to the same practical effects then I would be satisfied that my interpretation adequately explained the phenomenon under investigation.

For example, when examining the experience of being diagnosed with FMS I was aware that this concept could have a number of different practical effects including: illness validation, illness identity, access to treatment and benefits, and confirmation that nothing serious was wrong. In being able to identify all the different possible conceptions of diagnosis it was my belief that I would be able to establish credibility within the health care community scrutinising my findings. In advocating the application of this maxim Peirce (1878) was demonstrating the connection between reasoning and action and some allegiance with the principle of 'verification' (although he rejected the notion of absolute verification).

Pragmatism as described by Peirce (1878) was also defined by two other principles that were aligned with my beliefs about the generation of knowledge. The first was that the "purpose of action is to produce some sensible results" and the second that "there is no distinction of meaning so fine as to consist in anything but a possible difference in practice". As a practitioner-researcher I had a strong commitment to wanting to produce research that I believed would make a difference. My own knowledge and experience had led me to consider that gaining an understanding of what it was like to live with FMS might be able to influence the management of this patient group. In turn

this was underpinned by the need to produce a study whose methodological approach and study methods were able to produce results that answered the research question posed, but also had rigor.

William James (1907) further expounded pragmatic philosophy by proposing a theory of absolute truth that had embedded in it the notion that truth should have a practical and useful consequence to it. This is characterised by the following statement: "what difference would it practically make to anyone if this notion rather than that notion were true? If no practical difference whatever can be traced, then the alternatives mean practically the same thing and all dispute is idle" (James, 1907 p.94). Once more James (1907), like Peirce (1878), held the belief that attaining truth was possible, and once more showed some alignment with the principle of verification. He did this by examining all possible explanations and in so far as he was able to reject all alternatives when they showed no demonstrable difference in their practical effects. However, in contrast to positivism he did not believe truth to be something that was static but once more was irrevocably linked with experience. If knowledge and beliefs gained through scientific enquiry were to remain true then they had to be subject to scrutiny and revision with the acquisition of new or additional knowledge and experiences.

Once more this notion of what constituted truth fitted with some of my own assumptions about the generation of knowledge. As a physiotherapy practitioner I had been accustomed to using reflexivity within my practice of evidence based medicine. This regularly led me examine what I had observed in my practice with patients and reflect on this utilising my own experience together with current evidence. Through this process of self scrutiny I was used to having to consider my beliefs about what I considered to be best practice and revise them accordingly. As an experienced clinician however, I had acclimatised to the notion that I did not need to reject all I had previously considered to be true. Instead I was able to give consideration to whether the truth as I was now presented with was going to have any practical effect on the

patients I was presented with and thus recognise that it was possible for there to be multiple versions of truth. Utilisation of this concept of knowledge generation seemed appropriate to adopt within this research study.

Initially I had been concerned given the diverse traditions of qualitative research whether the reality that I presented about the experience of individuals with FMS would be considered a reflection of the truth. As I considered the possibility of attaining a single truth using the philosophical principles espoused by James (1907) I was able to recognise that it was possible for there to be multiple versions. What was critical to my study was how I searched for these within my study and challenged their existence, making this process transparent using critical reflection. In doing this I would be able to demonstrate why I had chosen the version of truth as I saw it and also the practical value that this held for the participants in the study.

Further support for the use of Pragmatism as a philosophical position to underpin my research study was gained by examining the work of John Dewey. Like James and Peirce, Dewey believed that truth could only be interpreted and understood in terms of its practical purpose and consequence. In contrast to James however, Dewey (1911/1978 p.67) did not hold with the notion of an absolute truth but proposed that knowledge became true 'instrumentally' i.e. it was ongoing and embedded within the domain of human experience. This is characterised by his statement that "truth in the final analysis, is the statement of things 'as they are', not as they are in the inane and desolate void of isolation from human concern, but as they are in a shared and progressive experience".

This supported my view that determining the truth about what it was like to live with FMS was not simply a case of asking participants and being given a straightforward answer. The discovery of this knowledge would be the consequence of the interaction between I, as researcher, and my research subjects. The experiences we had been exposed to before and during the research study, singularly and together, would

inform the knowledge that was generated and this knowledge would be unique to this set of circumstances. However, I was also able to consider how critical reflection of this and the ability to develop a theoretical explanation for the findings (that could be applied to other settings and circumstances) would increase the rigor of the study.

The work of Dewey (1930) placed emphasis on the value of human experience and behaviour in the generation of knowledge. He considered experience to be multi-faceted and encompassing three domains: physiochemical, psychophysical and experiential. This once more reflected the considerations that I had been giving to identifying the illness experience of FMS and the belief that investigating this should be done utilising a bio-psychosocial model of health and illness. As highlighted in the literature review there was a dominance of research exploring the biological and physical experience of FMS, but little to understand the psychological and social components of this illness experience, the focus of this study.

Like James before him Dewey (1930) also shared an appreciation for the role of language in understanding the experience of others. James (1907 cited in Kloppenborg, 1996 p.104) had described in his work *Pragmatism* how through communication knowledge of the human experience could be accessed when he wrote "All truth thus gets verbally built out, stored up, and made available for everyone. Hence we must *talk* consistently, just as we must think consistently". Likewise Dewey considered that it was possible to access the meanings attributed to individuals' experiences through the use of language. He highlighted (Dewey, 1927) that it was not the description of these experiences that gave rise to knowledge about their meanings and actions but an appreciation of symbols and shared understandings. He described how through linguistic communication "the results of joint experience are considered and transmitted. Events cannot be passed from one to another, but meanings may be shared by a means of signs" (Dewey, 1927 cited in Kloppenborg, 1996 p.105).

The emphasis of the role of language and communication in understanding the nature of human experience once more resonated with the aims of this study. It was my belief that through talking to individuals I would be able to gain access not only to a description of what had taken place but also gain some insight in to how this had been interpreted by the individuals I was studying. Whilst I was interested in gaining an appreciation of what had happened to them, I considered myself more concerned with understanding how and why these actions had taken place. I derived from this philosophy the notion that it was not sufficient to purely describe what had taken place as subjects spoke to me, but to look for shared 'signs' and 'symbols' that were common to their experiences. In doing this I believed it would be possible to develop a theoretical model that perhaps demonstrated 'cues' to look for in the stories that participants told.

The role of communication in being able to gain access to an individuals beliefs was further demonstrated in the work of Donald Davidson (1983) who advocated 'a coherence theory of truth and knowledge'. The work of Davidson mirrored that of the early pragmatists in that he considered experiential beliefs i.e. those based on human experience to be accessible through language and communication. However, he also conceded that not all beliefs were experiential i.e. beliefs might not be acquired solely through an individuals own experience but be a product of other beliefs they had.

Within my own study I was able to identify further similarities between the epistemological position of Davidson and myself. In understanding the experience of individuals living with FMS I was concerned that the beliefs individuals had might not be exclusively situated within the realms of their own experiences. Musculoskeletal pain is common within society and is regularly portrayed and discussed.. I was aware that individuals might hold a particular belief as a result of something that they had read or heard about, within the media or from others e.g. the belief that they had something seriously wrong given persistent tiredness and pain and a lack of diagnosis. It was my own perception that these beliefs were no more or less real than



those that were directly experienced by participants and pragmatism allowed me to reconcile this within my assumptions of what constituted knowledge about an individual's experience.

Davidson (1983) further countenanced the 'principle of charity' which resonated with concerns I had at the outset of the study. One of the reservations I had of performing a qualitative interview study was how representative this would be of their 'real' experience. This method of investigation was reliant once more on the interaction between the participants and myself. It required me asking the 'right' questions and them providing the 'right' answers. One of the quandaries I was faced with, in both instances, was 'how did I know what was right?'

Davidson's application of the notion of charity allowed for the assumption that the reality presented, by both myself and the participants, was for the most part true. It was not necessary for this to reflect absolute truth, but for this to present the perceived reality as projected by all parties. This reality was context dependent and both the responses given and their interpretation should be perceived as reflecting the 'truth'. This is demonstrated in the statement that "someone with a (more or less) coherent set of beliefs has a reason to suppose his beliefs are not mistaken in the main" (Davidson, 1983 p.232). I was able to reconcile this in part with the notion that it was unlikely for any one participant to portray beliefs that were all 'wrong', or for all the participants to be united in their portrayal of beliefs that were 'wrong'. If data saturation occurred then it was possible that what I was achieving was a notion of a shared social perspective and perceived reality.

Over time it became apparent that what I was investigating and interested in discovering was the perceived experience of living with FMS, not that observed by someone independent who could verify what took place. It was possible, for example, that the experience of seeing a physiotherapist for management of their condition might be perceived in a number of ways. Being prescribed exercises might be

perceived by some as best practice and an appropriate management strategy to increase exercise tolerance and employ a graded exposure approach to coping with pain and fatigue. In contrast others might feel that this demonstrated a lack of understanding and that they were being asked to participate in something that was beyond their capabilities and likely to only make things worse. I was able to realise that this was consistent with not of their being multiple realities but of their being multiple social perspectives and that "individual beliefs have content and meaning only in the context of a dense background of other beliefs, and it is the totality of our knowledge that provides the background to any knowledge claim" (Avis, 2003 p.999).

Further confirmation of my belief that pragmatism was an appropriate epistemological stance to adopt came when I considered its development by Richard Rorty. Rorty is considered by many (Kloppenber, 1996) to have been largely responsible for the resurgence of pragmatism in the second half of the twentieth century. He was instrumental in suggesting that the search for truth was futile and proposed that previous study and concerns with the correspondence theory of truth, theories of knowledge and language were misplaced. Rorty (1982, p.1) believed that all "truth" is just the name that of a property which all true statements share"

The notion that there was one universal method of research enquiry was rejected when he stated "Pragmatism....views science as one genre of literature or, put the other way around, literature and the arts as enquiries, on the same footing as scientific enquiries. Thus it sees ethics neither more "relative" or "subjective" than scientific theory, , nor as needing to be made "scientific". Physics is a way of trying to cope with various bits of the universe, ethics is a way of trying to cope with other bits:.....The question of what propositions to assert, which pictures to look at what narratives to listen to, comment on and retell, are all questions about what will help us get what we want or about what we should want" (Rorty, 1982).

Rorty (1982) can thus be seen to advocate the use of the most appropriate mode of enquiry to answer a specific research question combined with the consideration of how this method of enquiry would lead to the development of better ways of living. Aligned with this was the notion that reality was both constructed and found. I had been struck, when considering the epistemological position of some qualitative research traditions, that I did not believe it would be possible to deny my own beliefs and position when entering in to this research study. Presentation of textual data generated from qualitative interviews with individuals diagnosed with FMS would provide evidence of what it was like to live with FMS and a series of interviews would enable me to afford greater confidence to the beliefs that were held. However, I did not believe that description of this data alone would in itself provide knowledge to answer the research question.

In presenting the data I believed it was imperative to contextualise it and be transparent about the emerging evidence alongside my own subjectivity and position within the research. At every stage of the research study I did not consider the beliefs I formed to be occurring in isolation but to be a product of other beliefs that I held. These included beliefs based on prior experience, research literature and the nature of the social interaction occurring with individual participants. Transparency about these beliefs, through critical reflection, would allow me to demonstrate how I had come to place confidence in the conclusions I had arrived at. It would thus be necessary throughout the study to provide evidence, through my own reflexivity, of how I had come to hold the beliefs I had. This was a particularly challenge in this study given its longevity which provided the opportunity for prolonged periods of reflection. As a result, during the process of analysis in particular, my findings were subject to continued revision until I was confident that the beliefs I held at that moment in time would stand up to scrutiny by the academic and health care community I wanted to influence.

### **3.2.1.2 Critical reflection**

Critical reflection is considered (Freshwater and Avis, 2004 p.5) "A logic that provides justification for the way we use evidence to develop and test our theories...it suggests that there might be a universal process of analysing and interpreting evidence, irrespective of whether the evidence has been generated through qualitative enquiry, scientific investigation, or reflection on individual experience". The pragmatic epistemological stance I had taken was concerned with the notion that a claim surrounding knowledge generation is inextricably linked with reasons for 'why' that belief is considered to be true. This in turn is associated with the concept that beliefs are not generated in isolation but are inter and intra-dependent on other beliefs that are held. These beliefs might comprise past experience, research literature/evidence, and our belonging to a particular academic or practice community.

Engagement in this research study led me to question how my knowledge base and experience would influence not only the analysis and interpretation of this study but also the conduct of it. I was unable to align myself with a position that considered it possible or even desirable to 'leave behind' my past experience; I considered that this was the lens through which every practice, research or academic encounter was implemented, filtered and critiqued. For much of the study I was employed as a lecturer/practitioner in the speciality of musculoskeletal medicine. I considered myself in a unique position with regards to my research position and felt it had an important role to play in the conduct, analysis and interpretation, and ultimately the dissemination of this research study.

I was occasionally exposed to treating patients with FMS but this was the exception rather than the rule. Within the academic setting I lectured within the same speciality and was thus regularly accessing up to date evidence regarding the management of pain conditions, if not specifically FMS. I was also a part-time PhD student, constantly questioning the process and underpinnings of research. I was not a true 'outsider' with an absence of knowledge and able to view the data through 'fresh eyes' (Hansen,

2006) but neither was I a true 'insider'. There was a paucity of research literature that reflected the impact of such a role within a research study (Reed and Proctor, 1995). One concern I had was how my many roles had the potential to impact on the study and the knowledge claims that would be generated from it.

The adoption of critical reflection as an epistemological stance enabled to me embrace this inimitable position, as did its integration with pragmatic principles of knowledge generation. Pragmatism, as I had interpreted it, was concerned with: the production of evidence that practically made a difference; the notion that we should not be concerned with providing arguments for whether a single belief is true but with how new evidence fits and is supported within our totality of beliefs; the extension of charity and the assumptions that participants beliefs were a representation of their perceived reality; and the concept that knowledge is both constructed and found. Consideration of these principles led me to believe that the rigor of this study and the processes of both evidence production and generation needed to be assimilated with critical reflection throughout.

Critical reflection calls for researchers to "critically examine the internal and external consistency of his or her own beliefs (including the belief that 'correspondence to reality' is a reason to think that a belief is true!)" (Freshwater and Avis, 2004 p.6). It also places emphasis on the importance of recognising how evidence, beliefs and theories are inextricably linked, and this in part supported by consideration of the holism thesis proposed by Quine (1953). The holism thesis necessitates adopting an epistemological position that recognises that knowledge is not generated in isolation. This strongly resonated with my own difficulties in believing that I could ever truly set aside or 'forget' my own experiences and knowledge. However, mindful that this would always have some influence on my conduct and application within this study I needed (a) some external validation that this was an appropriate stance to have, and (b) a mechanism to demonstrate *how* this could be evidenced within the study.

My own experience of having read numerous qualitative research reports and methodology texts had led me to formulate the opinion that whilst the importance of reflexivity was described, and its practice within a research study stated, there was rarely any evidence of how this, should be or, was achieved. The consequence of this was that the validity and reliability of results appeared at times to rely upon statements made concerning the use of specific methodological approaches or traditions. It was my intention that if I was to be able to describe the totality of my beliefs I needed to embed critical reflection throughout the study. I needed to be able to demonstrate how the 'truth' portrayed in this study was not made "by appeal to the facts through verification but on a pragmatic basis of what makes sense of our total experience and system of beliefs" (Avis, 2003 p.999). This was clearly aligned with the Pragmatic epistemological position I had taken.

For example the research question I had posed was linked to: my experience of managing these patients and others with chronic pain problems; anecdotal evidence that made me believe others considered this group of individuals as 'heart sink patients'; the research literature that gave some insight into the themes that underpinned the experience of living with FMS; and finally the belief that answering this question might lead to an improvement in the understanding of what it was like to live with FMS and possibly an improvement in the management of the condition. Critical reflection would be necessary to consider the varying influences of experience alongside evidence and theory in how knowledge was generated.

Critical reflection asks that we consider that "evidence cannot be separated from the beliefs that influenced its production and, in turn beliefs derive their credibility from their success in handling the evidence" (Freshwater and Avis, 2004 p.7). I anticipated that I would be able to utilise this principle within data collection to examine whether the data being generated was able to answer the research question that had been posed. Scrutiny of the interview transcripts and a research diary/journal would allow an assessment to be made of how evidence and beliefs were being interwoven as the

research interview took place. I was conscious that data generated was always going to be a product of the researcher-participant interaction: the questions I posed would be a product of my own beliefs, with the answers derived a product of the beliefs of the participants. In turn the interpretation of the 'conversation' that took place would be governed by my beliefs once more. The data resulting from the study would not be the outcome of a passive linear process but be the result of active engagement that involved retrieval, consideration of what was important and subsequent 'making sense' contextually.

I was conscious that critics of the approach I had adopted to the generation of research knowledge might argue that it was subjective, non-repeatable and non-generalisable. My alignment with theoretical perspectives offered by critical reflection allowed me to answer these criticisms. The epistemological underpinnings of critical reflection and Pragmatism do not propose adherence to a specific 'scientific' method to validate research findings but instead propose the use of structured processes and transparency. Objectivity, repeatability and generalisability could be demonstrated by the use of an audit trail (Grbich, 1999) to detail the practical and theoretical process that took place. This would be underpinned by the detailing throughout of my own beliefs derived from experience and existing evidence (and recorded in a research journal) to demonstrate their use in the determination of what was of relevance in the data and its interpretation.

In addition I concurred with Freshwater and Avis (2004) that critical reflection could be associated with the use of hypothesis generation and testing which would further enhance the objectivity and generalisability of the research study being undertaken. Hypothesis testing in this instance differed from that advocated by falsification and verificationism whereby a formulaic scientific quantitative method is utilised to confirm the presence of a single truth. In this instance hypothesis generation is concerned with determining what beliefs might exist and the credibility and practical effects a given belief might have. Hypothesis testing then becomes a process of considering the

"connections between hypotheses and the evidence generated as the study progresses" (Avis, 2005 p.8). A belief or hypothesis is then strengthened by its ability to be 'predictive'.

Critical reflection therefore offers an opportunity to contribute to both of these processes. Broad initial hypotheses might be generated from experience, existing research literature and intuition; in this study, for example that being diagnosed would hold particular significance to these patients. Using the principles of critical reflection data analysis then involves searching within the interview transcripts for both confirming and disconfirming evidence of this phenomenon. Broad hypotheses are refined and challenged and new hypotheses generated as a result of emerging findings and their integration with literature and experience. As these new hypotheses arise they are applied to both existing and new data. Further evidence of credibility is then provided in the development of robust theory to support and predict findings. It is my opinion that it is not enough to state that reflexivity was used. Credibility and reliability will however be achieved through the embedding of critical reflection and the demonstration of transparency of this process so that others can witness how conclusions are drawn. In doing this validity can then be better demonstrated.

### **3.3 Methodology**

A study's methodology is concerned with the providing "justification for the methods of a research project" (Carter and Little, 2007 p.1317). It is concerned with description and evaluation of the research methods and thus develops understanding of the research process that was chosen as opposed to the results themselves (Kaplan, 1964). Methodological approaches to research enquiry are by their nature informed by epistemology. In my own research study I am able to demonstrate how my epistemological allegiance with pragmatism and critical reflection led me to believe that it would be possible for me to access knowledge about what it was like to live with FMS through qualitative research that did not show commitment to a particular 'tradition'.



It is acknowledged (Corbin and Strauss, 2008) that the choice of methodological approach used to undertake research should be underpinned by the research question that has been posed. The intention of this study was to elucidate the experiences of individuals recently diagnosed and for this reason a qualitative research approach was considered appropriate. Qualitative research is considered to be an appropriate mechanism for investigating social phenomena in natural settings to give "due emphasis to the meanings, experiences and views of all the participants" (Mays and Pope, 1997). It provides an opportunity to access information that would not be accessible in any other way, such as insights in to the social meanings that people associate with their health and their health experiences (Avis, 1999).

The literature review (Chapter 2) had highlighted how FMS does not fit a biomedical model but might be better explained by a bio-psychosocial model with multiple and individual intra- and inter-dependent components. There had been some identification within the existing literature of both descriptive insights and theoretical perspectives to describe the experiences of patients who live with FMS. However, these had not investigated those newly diagnosed, had not been performed in the UK and did not look at whether time mediated these experiences.

Given these determinants a quantitative approach was not considered an appropriate methodology, and it is not within the scope of this thesis to debate the merits and pitfalls of quantitative methods. It was acknowledged that this might have been appropriate if there had already been a detailed investigation of concepts of illness experience identifying 'what' occurs, alongside 'how' and 'why'. In this event it would have been possible to explore statistical relationships between the distribution, prevalence and incidence of such phenomenon (Crabtree and Miller, 1999). Instead answering the research question was considered more suited to an inductive qualitative approach that would allow the gathering of information and development of theory to explain the underlying processes taking place (Bowling, 1999). This would

allow the study of the complexity of the human experience without manipulation of the research setting.

The ontological position adopted was that I was interested in gaining access to the experiences of individuals newly diagnosed with FMS. I believed that gaining an understanding of the 'world' as presented by people that had FMS would enable me to access social perspectives that they might be unaware of and explain them using existing and emerging theoretical perspectives. My epistemological position had led me to consider that qualitative interviews would allow access to this information: conversations with 'sufferers' would encourage them to use their own language to present their construction of reality (Mason, 2002; Taylor, 2005). This section will provide further evidence and discussion of the methodological approach adopted within this study.

### **3.3.1 Data collection**

Interviews are considered an appropriate method of collecting data about peoples' social perspectives (Nunkoosing, 2005; Mason, 2002) and have the capacity to allow people to be the subjects and not objects of research, telling their stories in their own words. It was my opinion that my interviews showed some resonance with pragmatic assumptions concerning knowledge generation. These included the belief that language and communication provide the opportunity to access an individuals' beliefs and experiences of perceived reality (James, 1907; Dewey, 1930; Davidson, 1983) and the principle of charity (Davidson, 1983) i.e. that the reality presented would for the most part be true. This research study aimed to access the experiences and perceptions of individuals newly diagnosed with FMS. The use of interviews was justified for a number of additional reasons: they allowed access to patients experiences which are not readily observable e.g. physical relationships with spouses; they allowed access to events that have already taken place e.g. medical consultation; the initial onset of illness; they allowed investigation of reality as interpreted and

presented by the patients themselves i.e. rather what is the lived experience perceived by the patient as opposed to seen by the observer (Taylor, 2005).

Qualitative interviews are considered (Grbich, 1999; Hansen, 2006) to comprise three main types: unstructured/informal; guided/semi-structured; and formal/structured.

Semi-structured interviews were considered the most appropriate method for this study. This type of interview utilises an interview guide to focus the interview and can be utilised where there is already some background knowledge. I already had access to a number of beliefs concerning the research question being posed. These had been informed by my own experience, the research literature and intuition. It was possible given these beliefs to construct interview guides, at each stage of the study, that would provide potential avenues to explore in order to answer the research question.

Semi-structured interviews are carried out in-depth and use specific open-ended questions to access meanings and experiences. However, in contrast to structured interviews the questions can be re-phrased and the interviewees can be allowed the opportunity to contribute the information that they feel is important in portraying their experience of the truth, relative to the topic under investigation. In doing this they allow for the assumption that a researcher cannot know all the questions that need to be asked prior to entry in to the study (Rice and Ezzy, 1999). The flexibility inherent within this process can have a number of consequences: it allows for new and unconsidered areas of interest to be discussed and pursued and may contribute to a more relaxed atmosphere conducive to disclosure of more complex and sensitive issues in an in-depth manner (Bowling, 1999).

The interview and data collected is a product of social interaction between the researcher and researched (Mason, 2002); the stories told by participants are a product of the interview and their telling is facilitated by the skills of the interviewer (Nunkoosing, 2005). The information provided may be "only one facet of the multiple aspects of 'truth'" (Grbich, 1999 p.87) and the validity of the interview as a research

tool is supported by the argument that all narratives that the participant chooses to share are important in contributing to the understanding of their experience (Nunkoosing, 2005). This once more resonates with the perspective offered by pragmatism (Dewey, 193) that the research enquiry and generation of knowledge is a product of both the researcher and the researched. Additionally it aligns with the belief that searching for a single truth is futile and that we should be concerned with "what effects, that might conceivably have practical bearings" (Peirce, 1878).

The use of semi-structured interviews linked with the position of critical reflection in the process of hypothesis testing, refinement and generation. Crude and broad hypotheses were evident at the beginning of the study both in the objectives of the study and in the questions that were present within the initial interview guide. The emergent nature of the questioning that took place during this style of interview, allowed for existing beliefs and knowledge to be tested against the data that was arising. Throughout the interview this information was reflected upon to give rise to new avenues of questioning to be attended to. As a result hypotheses were refined until additional questioning, both of an individual or other interviewees, gave rise to no further information that changed the hypotheses.

In considering the choice of interviews as a methodological approach I also considered in some depth how this approach had been influenced by feminist theories, the affiliation I had with these, and how I might choose to include them within my own study. The literature review had highlighted how FMS is a condition that is contested and predominantly affects middle aged women. Feminist research and feminist theories have been concerned with: gender, the presence of power relations within research, the oppression of women and the potential for research to be exploitative and political (Grbich, 1999; Hansen, 2006). Advocates of this approach have argued for "the exploration of women's distinctive experiences" (Anderson et al, 2004) and that this should be performed by other women who are able to share ways of "seeing, knowing and being" (Grbich, 1999).

When considering the beliefs I held on the experience of what it was like to an individual with FMS, I began this study having some empathy with feminist theories. However, I had reservations with believing that my position as woman within this study would necessarily afford me "epistemological privilege" (Mason, 2002 p.192). However, as a clinician, who for a long-time had considered herself as an advocate of holistic health care and the bio-psychosocial model I did share some of the methodological practices that feminist researchers appeared to endorse.

I showed particular alignment with the position that feminist research has adopted concerning the researcher and the researched. Feminist research has placed emphasis on the potential power relationship within research and the importance of avoiding exploitation of those that are vulnerable. Proponents of this perspective (Oakley, 1981) have highlighted how the power relationship can change within a study. Initially the participant might share the balance of power in determining whether or not to participate. As the study progresses and the interaction between both parties evolves it is possible that this power dynamic changes to reflect the level of rapport developing between the two parties. It is inevitable however that once analysis and dissemination take place that the power shifts to the researcher who is in control of explaining the findings and determining where and to whom they are reported.

This in many ways showed parallels with my own experience as a clinician; I had always felt, irrespective of gender, that it was important to attempt to attain equality in the relationships I shared with patients. It was important for me to ensure that both I and my patients had the opportunity to shape the clinical experience and negotiate management plans. Whilst I was able to acknowledge that the research interview was not a therapeutic interview, there were a number of similarities I was able to draw upon and felt important to implement in the research setting.

Feminist research has a tradition of rejecting closed/structured interviewing (especially in the research of women by other women) as it has the potential to create both a hierarchical relationship and “objectify our sisters” (Oakley, 1981). Instead it favours unstructured interviews that place emphasis on both parties within the process. This resonated with my belief that both parties should have an opportunity within the research interview to ask questions that were considered important and relevant to the purpose of the study. Similarly both parties should have the opportunity to answer or not.

Feminism also champions the use of reciprocity and argues that in asking the participant to share and engage within the research study (and in this instance research interview) so the researcher should be prepared to do the same. The purpose of this appears in part an attempt to reduce power and exploitation from the research relationship. However, it was my opinion that to do this could have the potential to enhance exploitation. By revealing values, emotions and life experiences I considered the possibility of ‘confusing’ the participants of the nature of the research and relationship. I thought it possible for both the researcher and researched to be considered as equals without the researcher divulging anything more than superficial personal information and social ‘chit-chat’ within interactions that took place. To do anything more might in fact appear coercive and distort the perception of the interaction. The purpose of the interaction was not to establish friendship but rapport; to give the impression that friendship was being developed could, in my opinion, lead to increased vulnerability and potential abuse of both parties (Gribich, 1999).

The literature review (section 2.2.4) had identified that the prognosis for patients was poor and that the majority would continue to suffer symptoms. As a part-time PhD student the time allocated for performing my research study was 5 years plus write-up. This allowed me to consider the potential for using a temporal series of interviews when I was developing my research question. There was no research evidence to indicate whether there was a particular time frame time at which any process of

adaptation takes place or whether the experiences of individuals with FMS are in fact mediated by time. An initial 'map' of the study allocated a possible time frame of 3.5 years for data collection to take place. A series of interviews improved the potential for a more intimate research relationship to be developed between myself and the participants i.e. enhanced trust and rapport. It also provided the opportunity to revisit areas of interest as well as explore new topics that arose.

In-depth interviews conducted on multiple occasions also increase the likelihood of sensitive and personal information being divulged given the potential for greater trust to be established. Once more this increases the chance of participants being exposed to feelings of exploitation and vulnerability. The literature review has alluded to the fact that there may be an increase in incidence of abuse (De Civita et al, 2004; McBeth et al, 2001; Alexander et al, 1998; Boisset-Pioro et al, 1995) amongst individuals experiencing the symptoms of FMS. Feminism, along with other qualitative methodologies, shows a strong commitment to reflexivity. I considered that it would be especially useful to utilise this both within and after the interviews in an attempt to minimise the potential harm from the questioning process. Reflexivity would allow me the opportunity to examine and consider the role that I played in the interviews to ensure that I was facilitating this process and not being in anyway exploitative.

### **3.3.2 Sampling decisions**

This section has highlighted how research methodology is concerned with the description, justification, explanation, justification and evaluation of the methods used in a research study (Carter and Little, 2007). The use of an appropriate sampling strategy to answer the research question posed would enhance the rigour of the study. I was concerned with discovering what it was like to be newly diagnosed and live with FMS and, in accordance with this and my epistemological stance, I determined it appropriate to adopt a purposive sampling strategy (Mason, 2002). Purposive sampling is considered (Bowling, 1997; Taylor, 2005; Hansen, 2006) a process that allows the selection of information rich cases to answer the questions of

focus and as a result "the researcher samples on the basis of wanting to interview people who are relevant to the research question" (Bryman, 2004 p.334).

Theoretical sampling is a type of purposive sampling and was utilised to allow for the selection of information rich cases to answer the questions of focus (Bowling, 1997; Taylor, 2005), the identification of individuals who had the potential to demonstrate diversity, and the opportunity to evolve the sample design as the study developed (MacDougall & Fudge, 2001). It is an iterative process that involves continued movement between data collection and analysis until theoretical saturation is reached (Bryman, 2004) i.e. no further issues are emerging from the data and no further refinement of theories is required. This process has parallels with the previous descriptions of hypothesis generation and testing in qualitative research; it requires continued critical reflection to ensure that there is adequate evidence presented combined with transparency to demonstrate the validity and reliability of the theories offered. Until such time that theories and hypothesis testing require no further refinement sampling should be continued.

Given this caveat the sample size in qualitative research interviews is often not known until the research is completed (Bluff, 2005). The determination of sample size in qualitative research can be influenced by (a) a pragmatic approach and includes issues of how many subjects can be researched and evaluated in the time frame allowed and (b) theory-saturation which encompasses the notion that a point is reached where no further new issues are emerging from the data (Corbin & Strauss 1998, cited in Bluff, 2005 p.151). Both approaches have the potential to be "ad-hoc and unsystematic" (Mason, 2002 p.135) with questions regarding how saturation can be demonstrated. However, samples should allow access to sufficient data to address the research question, allow the development and testing and development of theoretical perspectives, and be dynamic and ongoing.



Sample size in qualitative research is typically small and this in part reflects the complexity and volume of the data that is frequently collected as well as its association with theory and hypothesis generation. The association with in-depth studying places the emphasis on the quality of the information generated rather than the quantity. Whilst data could be considered non-representative of the larger population, theoretical generalisability can be evidenced through the presence of sociological theory throughout the research process (Avis, 1999) and detailed description of the social context.

Previous studies using qualitative interviews and similar sampling strategies had utilised a sample size that ranged from 7-40 (Hellstrom et al, 1999; Asbring, 2001; Hallberg & Carlsson, 2000; Asbring and Narvanen, 2002). I anticipated that a similar number of participants might be required in this study for data saturation to be reached but remained open to the fact that given the wide age range of participants it might be necessary to interview more participants than this in order to gain sufficient data and an adequate breadth and depth of experiences.

### **3.3.3 Ethical issues**

The ethical basis of a research study is as important as its validity and reliability (Avis, 1999; Hansen, 2006) with a study that fails to demonstrate rigour being itself unethical. It is recognised that qualitative research can result in detailed and personal exchange of information that may be of a sensitive nature or lead to ethical dilemmas (Silverman, 2002). It is important that when conducting this type of research due consideration has been given to how this will be dealt with whilst maintaining the confidential and anonymous nature of the disclosure in the research context. Participants in qualitative research are rarely susceptible to physical risks but are more vulnerable to psychological harm during data collection and dissemination. Medical ethics is typically associated with four principles: beneficence, non-maleficence, autonomy and justice which should be applied equally to medical research as they are to treatment.

The principle of beneficence is concerned with "a moral obligation to act for the benefit of others" (Beauchamp and Childress, 1994 p.260). This has been considered in this research study with one of the objectives being to develop a theoretical model that might have the potential to assist clinicians in understanding the experience of this client group and assist in developing more patient centred management. Extending the principle of reciprocity, beneficence is also demonstrated in the decision to answer questions that are asked regarding FMS if broached by participants during the interview study but not to address issues relating to their individual case and management.

Non-maleficence is concerned with not inflicting harm intentionally and shows alignment with the test of 'best interests' (Beauchamp and Childress, 1994). The literature review, Section 2.2.6 had highlighted the potential for sensitive issues to be raised and discussed by participants and the consequences of this had to be considered. During the interview it was possible that disclosure could result in distress as individuals confronted issues surrounding their experience of living with a contestable and chronic illness (Irhofen, 2005). Recognition of the principle of non-maleficence meant ensuring that this could be attended to and participants given the opportunity to: discontinue the interview (and indeed participation in the study); compose themselves and continue with the study; have the audio-data regarding discussion of this issue erased; seek further help regarding the issue that had distressed them.

It was also important to consider what mechanisms I would need to have in place if participants disclosed information that might need further action e.g. suicide, past abuse that had never been reported. Prior to commencing data collection I aligned myself with the notion that this would need to be linked with autonomy and allow the participants to determine what action, if any, they wanted to take. It was my opinion that not to raise these issues in questioning or not discuss them when they arose

could in itself be considered unethical. It was in their 'best interests' to allow them to discuss those issues that reflected the 'true' experience of living with FMS but that the extent of disclosure, and any necessary action, should be determined by them.

Further opportunity for the principle of non-maleficence to be breached can occur in the process of dissemination and reporting of study results. Given the small sample size and purposive nature of the sample it is possible that individuals might be able to recognise themselves within both the results that are described and the quotations that are used as evidence to support findings (Hansen, 2006). Pseudonyms can be utilised to limit this potential breaching of confidentiality although subsequent descriptions of the participants to contextualise their experiences can reduce the effects of this, especially where particular communities of interest are small already.

Non-maleficence also has potential to occur as a result of misunderstandings regarding the research relationship. Given the emphasis placed on reciprocity and the development of rapport it is possible that participants might misinterpret the nature of the research relationship. Within this study given the serial interviews and the potential for discussion of sensitive issues this was of some concern. As a result I considered it would be appropriate to engage in social conversation but would be inappropriate to divulge my own emotions and concerns. In this way I would attempt to avoid confusion developing over the nature of the relationship that I had with each participant.

The principle of autonomy is related to the respect of autonomous persons i.e. the right of individuals to hold views and make choices based on their individual values and beliefs (Childress and Beauchamp, 1994). The relevance of this principle can be evidenced through the provision of consent within a research study and the need "to ensure that participation is based on each individual coming to his or own assessment of possible harms and possible benefits" (Avis, 1999). The gaining of informed consent requires the provision of sufficient information for patients to be able to

determine this. Given the repeated interviews within this study it was essential that consent was ongoing. Also, given the emergent nature of the study and the potential questions and answers that might have arisen it was important to consider consent to participation not just at the beginning but also at the end of each interview once participants had time to reflect on what had been discussed.

The fourth principle of medical ethics is justice and this is concerned with fairness and dessert (Childress and Beauchamp, 1994). Within the context of qualitative research this can be evidenced through the consideration that is given to individuals being treated fairly and equally. Within this study I considered that this could be attended to through the use of reflexivity. I considered it essential that each participant be given equal opportunity to be interviewed in a manner that was appropriate to our interaction. I did not consider it ethical to interview each individual in the same manner: their individual circumstances (age, gender, social class) should be taken into consideration to give them an equal opportunity to engage in the interview. Critical reflection involving listening to interviews, reading transcripts and consultation of my researcher diary could assist in this process.

Qualitative research in the context of this study is non-therapeutic research and aims not to provide improved health outcomes for participants but to improve knowledge that is unlikely to benefit them directly but might benefit others. Ethical approval is required from the appropriate research ethical committee and consent needs to be obtained from the participants (Montgomery, 1998). Participants should be given details of the purpose of the investigation, how the study will be conducted, how confidentiality, privacy and anonymity will be maintained, how the research might be disseminated and a written statement that they may decline or withdraw at any time from the study (Montgomery, 1998; Royal College of Physicians, 1996).

The potential ethical issues that might arise in a study of this nature have been described the basis of which was aligned with the Declaration of Helsinki (1964).

Ethical approval for the study was obtained from the Local Research Ethics Committee (Appendix 2) and the Research and Development department of the NHS Trust where participants were to be recruited from.

### **3.3.4 Data Analysis**

The purpose of qualitative data analysis is to “summarise and organise the data in such a way that research hypotheses can be tested or the research question answered” (Avis, 1999). Within the context of qualitative research this is not an isolated task but linked with the epistemology, methodology and method of the study. It can be seen to be composed of two components: data management and data interpretation. Data management is concerned with the coding, indexing and sorting of the data. This is in contrast to interpretation that is associated with the identification of themes, meaning, relationships and explanatory theory. These two components do not occur independently or sequentially but are interwoven and incorporate the process of critical reflection to ensure that all data are explored and satisfactory interpretive or theoretical explanations have been generated.

Within the qualitative research paradigm “there are no hard and fast ‘rules’ for how qualitative data should be analysed” (Hansen, 2006 p.138) and reflecting the emergent nature of many qualitative studies I held allegiance with the belief that due consideration has to be given to the possibility of the analytical process utilised being flexible. The pragmatic perspective (Rorty, 1982) of this study also gave emphasis to utilising the most appropriate mode of enquiry, and by association analysis, to answer the question posed. At the commencement of the study I considered iterative thematic analysis an appropriate method to employ to identify recurrent themes and meanings of interest within the data (Hansen, 2006). However, Chapter 4 will focus attention on how this evolved with narrative analysis being eventually introduced as a method more suited to explaining the emergent findings.

The approach to analysing qualitative data is associated with the epistemological and methodological position of the research study; this itself is linked with the research question and aims. As a method of enquiry it is essential that this process is logical and systematic with due attention given to fact that it is a value laden process (Green et al, 2007). The suggestion is made (Green et al, 2007) that rigor within data analysis is demonstrated by the transparency of four stages: data immersion, coding, and the generation of categories and themes.

Immersion in the data takes place when the interview is conducted, transcriptions made and transcripts read. Coding of the data involves 'tagging' the data with descriptive labels that identify potential statements of interest, and takes into account the context in which they were generated. The codes generated are rarely definitive and face continual refinement as continued data collection, analysis and critical reflection 'test' their validity. The creation of categories is concerned with an attempt to link codes and highlight relationships between them whilst theory generation attempts to present higher level evidence for the findings, offering interpretation rather than mere description. Throughout this process critical reflection is utilised to make visible how data, evidence, beliefs and intuition are interwoven. (Freshwater and Avis, 2004).

Irrespective of which model is adopted there have been a number of recent critics (Carter and Little, 2007; Green et al, 2007; Avis, 2005; Freshwater and Avis, 2004) of the tendency for much qualitative data analysis to fail to make explicit the analytic process that has been undertaken. As a novice researcher this stance aligned with my own difficulties at the outset of the study in understanding how findings 'emerged' from the data. Practical examples of how this occurred were difficult to find. It is my intention in the next Chapter to detail how this process took place in the context of this study in the hope that it will enhance the interpretive rigor of the findings.

At the beginning of this study I had posed a research question to which I had a rough explanation based on my prior experience, the research literature and intuition. As

described previously it was also my belief that qualitative data could be subject to hypothesis testing and generation, and thus supported a strategy of analytic induction (Bryman, 2004). Analytic induction and iterative thematic analysis both advocate a cyclical process of data collection and analysis: data is collected, subject to analysis, and then this analysis is utilised in the return to the field to guide further data collection (Bryman, 2004; Hansen, 2006; Grbich, 1999). The process of further data collection, informed by the analytic process, involves modifications to the sampling strategy/selection, interview guide, and research question as themes emerge from the data. This process requires immersion in the data; it necessitates the ability to continually refine the emerging themes and hypotheses in the light of the new data. This is integrated through critical reflection with a return to the evidence base and re-appraisal of personal beliefs that might influence the newly generated or refined hypotheses (Freshwater and Avis, 2004).

As a practising clinical physiotherapist this was very similar to the process of reflection that I used when implementing evidence based medicine and mirrored what happened when new experiences with patients, or new research literature, required me to modify my clinical reasoning concerning management of a given patient. It also allowed me to accommodate the tension I had felt about my inability to reconcile my position within this research study as neither an 'insider' or 'outsider'. This permitted me to have an initial hypothesis and consideration of what themes/hypotheses might be generated at the outset of the study. However, it also allowed me the opportunity to remain open to the fact that I might have 'got it wrong' and thus be receptive to the emergence of alternative explanations. How this was practically implemented will be demonstrated in the next Chapter.

As with other methods of qualitative data analysis iterative thematic analysis also involved the process of coding the data. Coding is broadly considered a process of attaching 'labels' to data to highlight points and areas of interest (Grbich, 1999; Bryman, 2004; Hansen, 2006). These might reflect the words or language that

participants use, descriptions of events that are occurring or decisions about sampling that might need to be made. The coding process is not linear and frequently follows a circuitous path, as coding develops throughout the course of a research study and this will be evidenced in Chapter 4.

Expert opinion (Bryman, 2004; Hansen, 2006) advocates the commencement of coding as soon as possible and encourages, where possible, the transcribing of interviews by the researcher. It is suggested that this "increases familiarity and expands a researcher's ability to make connections between different aspects of the data" (Hansen, 2006 p.149). Coding is done alongside the review of field notes and this process reinforces the iterative nature of this method of analysis: it guides movement from the 'field' to data analysis and interpretation, with critical reflection then being utilised to influence further data collection and a repeat of the process.

In the early stages coding can often entail the highlighting of key areas of text alone. As this is developed decisions are made regarding the 'labels' that have been assigned: refinement then takes place to ensure they adequately describe the phenomenon being discovered and also that there is no duplication i.e. the same code isn't being used twice using different language (Bryman, 2004). Further coding is associated with the emergence of sub-themes that group together a number of 'key issues'. Scrutiny of these should highlight relationships between these areas of interest and further expansion of coding is witnessed with the development of global themes demonstrating connections between the sub-themes.

Throughout the process of data analysis and data collection there is a return to the data when new codes emerge, and thus they are tested against the development of both previous and newly emerging data. Eventually, the development of global themes is used to place an emphasis on movement of the analytic process from one of mere description to one where theoretical explanations are offered. This movement to achieve theoretical understanding is associated with increasing the rigor within qualitative research (Green et al, 2007; Avis, 2005) and can be likened to the



development/refinement of hypotheses. The whole analytic process is underpinned throughout by attendance to principles of critical reflection (Freshwater and Avis, 2004) and consideration of how the emergent codes are examined against existing evidence, experience and communities of beliefs. It is within this schema that the movement to data interpretation becomes highlighted and rigor is increased as transferability becomes facilitated.

### **3.3.5 Rigour**

The rigour of a research study is concerned with the quality and trustworthiness of knowledge claims that are made (Hansen, 2006). In the absence of formulaic criteria (the likes of which are available within the quantitative paradigm) there has developed considerable debate about the criteria by which qualitative research should be judged (Carter and Little, 2007; Onwuegbuzie and Leech, 2007; Meyrick, 2006). This is compounded by the numerous and varied traditions of qualitative enquiry each with their own unique epistemology, ontology and methodology. This Chapter has highlighted through its discussion of epistemology and methodology how qualitative research findings in this study: usually represent one version of truth but acknowledges there may be others; are able to defend their claim to knowledge generation; and are able to demonstrate a discernible effect on practice. It embraces the notion that knowledge is contextually situated and a product of the interaction of the researcher and participants.

In recognition of this the rigour of a qualitative research study is primarily concerned with establishing credibility of the process of data collection, analysis and knowledge claims that are made. It has been advocated (Meyrick, 2006; Avis, 2005 ; Freshwater and Avis, 2004) that all qualitative methods of investigation adhere to logical and systematic processes that are consistent with the principles of transparency and critical reflection. This aligns with the notion that "the distinguishing mark of all good research is the awareness and acknowledgement of error" (Oakley, 2000). In addition to credibility it is also important to demonstrate: dependability- how

consistent and accurate are the conduct and findings of the study; transferability –can the results be transferred to other similar settings and participants; and confirmability- is their transparency in how the findings and conclusions are arrived at and meet the study objectives (Holloway and Freshwater, 2007). Consequentially it has been suggested that a number of strategies can be employed throughout a research study to enhance and make visible how rigour has been attended to (Meyrick, 2006; Hansen, 2006) and these have been discussed throughout this section. These are detailed with reference to this study in table 3.

### **3.4 Conclusion**

This chapter has attempted to demonstrate the epistemological and methodological foundations of this study with particular reference to the employment of qualitative research interviews to answer the study question 'what are the experiences of individuals newly diagnosed with FMS and do they change over time'. It has highlighted the role that both pragmatism and critical reflection have had in the choice of methodological approach and given some indication of how the problem of rigour has been addressed. The next Chapter will detail the study methods, the practical processes adopted within this study and demonstrate their emergent and iterative nature.

Questions to address rigour	Strategies adopted to promote rigour
Is the research question appropriate to the method of enquiry?	Question concerned with gaining in depth insight into lived experience of FMS. Requires description and interpretation of subjective meanings of participants.
Is the topic relevant?	Gap in the research literature investigating FMS illness experience (a) longitudinally, (b) following diagnosis and, (c) in the UK
Is the researcher epistemological/theoretical stance identified?	Researcher position, background and influences described.  Epistemological perspectives of pragmatism and critical reflection defined.
Is the method appropriate to meet the aims and objectives of the study?	Semi-structured interviews allow access to participants perspectives and beliefs regarding the illness experience.
Are ethical considerations demonstrated?	Local ethics and R&D approval will be sought.  Consent will be gained at all stages of the study.  Confidentiality of participants and data will be respected.  Mechanisms will be described to manage psychological distress that occurs.
Is there enough detail given of who was sampled and why?	Theoretical sampling used to capture experience of those newly diagnosed with FMS.  Inclusion/exclusion criteria will be described to limit enquiry to this phenomenon  Sampling will be performed and developed until

Is there sufficient detail of how data were collected?	<p>data saturation is reached representing themes being generated.</p> <p>Method will describe a systematic process including: research context; sample recruitment and design; nature and conduct of the interview. Critical reflection and the use of an audit trail will be used to demonstrate data collection that is responsive to the emergent analysis.</p>
Is there transparency and a systematic process of analysis?	<p>Transparency will be evidenced of any change in focus of the study.</p> <p>Critical reflection and an audit trail will be used to detail the process of analysis and the integration of evidence, data and researcher knowledge.</p>
Are the results and conclusions grounded in the data?	<p>Examples of textual data will be presented to support the major findings</p> <p>Discussion of the results will be integrated with relevant literature</p>
Are the results transferable?	<p>Sufficient detail will be given of the context to allow the results to be transferred to other patients/setting</p>

**Table 3. To demonstrate how rigour has been addressed within the study:  
adapted from Meyrick 2006**

## **CHAPTER 4**

### **THE STUDY METHOD**

#### **4.1 Introduction**

Chapter 3 introduced the commitment of this research study to the belief that epistemology, methodology and study method are linked and that all three of these domains are influenced by the research question, the research objectives and the position of the researcher. It highlighted that transparency regarding these domains should increase the rigour of this study. The objectives of this study were:

- to identify and recruit individuals newly diagnosed with FMS by a Rheumatology Consultant in a Secondary Care Setting
- to gain local ethical and R&D approval
- to use semi-structured qualitative interviews to capture the lived experiences of individuals newly diagnosed with FMS
- to capture the lived experiences of individuals newly diagnosed with FMS
- to explore whether time mediated the experiences of diagnosis and living with FMS
- to identify what if any meanings could be inferred from their experiences
- to develop a theoretical model to explain the lived experience of individuals with FMS that might facilitate their holistic assessment and management by clinicians

Accordingly the epistemological position of this study was defined i.e. that it is influenced by the theoretical and philosophical perspectives of pragmatism, critical reflection and feminism. It also highlighted the methodological commitment to the qualitative paradigm and demonstrated how and why the theoretical and philosophical perspectives have been chosen.

The study method is the "practical activities of research: sampling, data collection, data management, data analysis and reporting" (Carter and Little, 2007 p.1318). This

chapter will detail this process of research in action, and focus attention upon the iterative nature of the study. It will place emphasis on the emergent process of data collection and analysis, and detail the movement from iterative thematic analysis to narrative analysis. Consideration will be given to how this process was not just influenced by the methodological and epistemological approach chosen but was a product of the longitudinal nature of the study and my own personal circumstances. In accordance with critical reflection the use of my researcher diary will be incorporated to enhance the transparency of decisions that were made. Further discussion of reflexivity and my role within the study will be presented in Chapter 6.

This study will be presented in two sections: the first section will define the design at the outset up to the point where data collection was commenced; the second section will describe the fieldwork, highlighting the emergent nature of the design.

## **4.2 The study design**

This section describes the study method as it had been anticipated, prior to the start of data collection. Discussed in this section will be: the research context; ethics, consent and confidentiality; sample design; sample recruitment; data collection; and finally data analysis.

### **4.2.1 The research context**

This study took place within a large inner-city NHS Trust where it was believed that the majority of local patients considered to have FMS were referred for assessment, diagnosis and management by Consultant Rheumatologists. The Rheumatology Department at the time had 5 full-time Rheumatologists and saw 2491 new patients in 2004-5 (the period of time during which participant recruitment commenced). No data was available on how many of these patients were diagnosed with FMS but anecdotally Consultants reported they all saw a couple of new cases each week. When the study began my clinical practice involved working alongside the Rheumatologists, within a triage service to which patients, with non-inflammatory

musculoskeletal conditions were referred. A relationship was established with the potential to provide support to the research study taking place and facilitate participant recruitment. The support of local stakeholders also increased the opportunity for findings to be disseminated and integrated into practice locally, if appropriate.

When this study began the typical pathway to diagnosis for patients with FMS involved an assessment by the Consultant Rheumatologist. Consistent with the literature review (Wolfe et al, 1990) the pathway to diagnosis of FMS at the Trust was a process of exclusion. Discussion with the Rheumatologists had identified that assessment of a patient presenting with potential symptoms of FMS would typically include a physical examination with assessment of the ACR recognised tender points (Wolfe et al, 1990). This would be accompanied by routine blood tests for inflammatory joint and soft tissue disorders and thyroid function, other potential causes of the symptoms, with the belief that these would normally be negative.

Where fibromyalgia was the most likely explanation of their symptoms the diagnosis was explained, reassurance given and the patient given a copy of the ACR fibromyalgia leaflet (ARC, 1999). All patients were advised of the benefit of exercise and the majority of patients then received a review of their medication and the provision of a tricyclic antidepressant drug e.g. amitryptilline to help with their sleep. Further treatment e.g. physiotherapy or referral to the local pain management programme (PMP) was organised for some patients but there was no explicit rationale or pathway that determined whether or not this took place. No follow-up appointment was routinely made and patients were informed in writing of the results of their blood tests, which were usually negative. Further follow-up was made if investigations had identified objective markers warranting further examination. Management of their condition was thus transferred back to the patient and their primary care practitioner.

Access to the participants was initially instigated by discussion with the Clinical Director (one of the Rheumatology Consultants) who agreed in principle to being

involved in recruiting participants. A copy of the research proposal was then given to the remaining Rheumatology Consultants and this was accompanied by a presentation (from myself) in the monthly Rheumatology Directorate meeting. This provided the opportunity for questions to be asked and for clarification of the project. There were no concerns raised and they agreed to being involved in the process of recruitment. At this stage they all expressed a concern that being involved in recruitment might result in them being perceived as having a particular 'interest' in FMS.

#### **4.2.2 Ethics, consent and confidentiality**

Section 3.3.3 identified the potential ethical issues that might arise in a study of this nature, the basis of which was aligned with the Declaration of Helsinki (1964). Ethical approval for the study was obtained from the Local Research Ethics Committee (Appendix 2) and the Research and Development department of the NHS Trust where participants were to be recruited which initially reflected a mixed methods design. Approval was granted for the interview study, and when the design changed to a longitudinal study with three interviews further approval was sought and granted (Appendix 2).

During the process of recruitment consent to be contacted by the principal researcher was indicated by the return of a reply slip in a pre-paid envelope (Appendix 3) and the consent form (Appendix 4): this was not completed until the first interview when I had the opportunity to explain the study in person and ensure that participants understood what was being asked of them. Participants were given the opportunity to decline participation or withdraw their data from the study at any time. Thus at each stage verbal consent was to be obtained including:

- after each interview when each participant was asked if they were prepared to be contacted for a further interview if necessary,



- following an interview they were asked if they consented to the data collected being part of the research, given the sensitive nature of some of the disclosures, adhering to the principle of non-maleficence,
- when participants were contacted for a further interview they were reminded of the nature of the study and asked if they still wanted to participate

Throughout the study participants were assured of anonymity and confidentiality. The data collected was stored securely: computer data was password protected and written information kept in a locked filing cabinet. A master list of participants was kept on a database after which they were identified by number only. All audio and written data was identified by subject number only. They were assured that they would be identified by number only within any written report or dissemination of the findings.

Further anonymity was offered by giving participants the choice of where the interview was to be conducted. It was not possible to give them a completely free choice of venue but the opportunity for this to take place at the University, the hospital or their own home conferred them the opportunity for some privacy. It was anticipated that there might be discussion of issues that were of a sensitive or distressing nature and this had been highlighted in the discussions of the project with the Rheumatologists. Given the need to adhere to the principle to 'do no harm', it had been decided that if participants demonstrated signs of marked psychological distress e.g. suicidal thoughts, these would be discussed with the Rheumatologist and they would either be reviewed by them or referred to a clinical Psychologist

#### **4.2.3 Sample design**

Section 3.3.2 identified that a theoretical sampling strategy was adopted and individuals newly diagnosed within a Secondary care setting recruited to reflect the setting in which most patients received their diagnosis. The ACR criteria (Wolfe et al, 1990) were established criteria for inclusion of FMS patients into research studies and also reflected the criteria that were most commonly used by the Consultant\*

Rheumatologists to diagnose their patients. To ensure homogeneity of diagnosis and restrict diagnosis to the experience of FMS these diagnostic criteria were utilised in this study. FMS can affect both adults and children with its peak prevalence in adult women. It was my intention to sample adults of all ages and both genders in order to gain a broad insight into the experiences of living with FMS, although I was aware of existing literature that suggested that gender may influence the experience of FMS (Paulson et al, 2003; Soderberg et al, 2003; Paulson et al, 2002; Soderberg et al 2002; Raymond and Brown, 2000). The exclusion criteria were intended to restrict the experiences to issues related to FMS rather than other chronic illness and to prevent problems of recall and inaccurate translation which would affect the validity of the data.

Inclusion criteria were:

- Individuals with a first diagnosis of FMS according to ACR criteria (Wolfe et al, 1990) by Consultant Rheumatologist
- Adults
- Male and female.

Exclusion criteria were:

- Individuals aged 17 or under ,
- Individuals who did not have FMS
- Presence of other co-morbidities such as inflammatory pathology, widespread OA, chronic fatigue syndrome
- Presence of severe mental health problems e.g. schizophrenia, manic depression for which they were undergoing treatment in secondary care
- Individuals who were unable to communicate in spoken English and required a translator
- Individuals who did not wish to enter the study.

Previous studies using qualitative interviews and similar sampling strategies had utilised a sample size of 7- 40 participants (Henriksson, 1995; Hellstrom et al, 1999;

Asbring, 2001; Hallberg & Carlsson, 2000; Asbring and Narvanen, 2002). I anticipated that a similar number of participants might be required in this study for data saturation to be reached but remained open to the fact that given the wide age range of participants it might be necessary to extend this in order to gain sufficient data and an adequate breadth and depth of experiences.

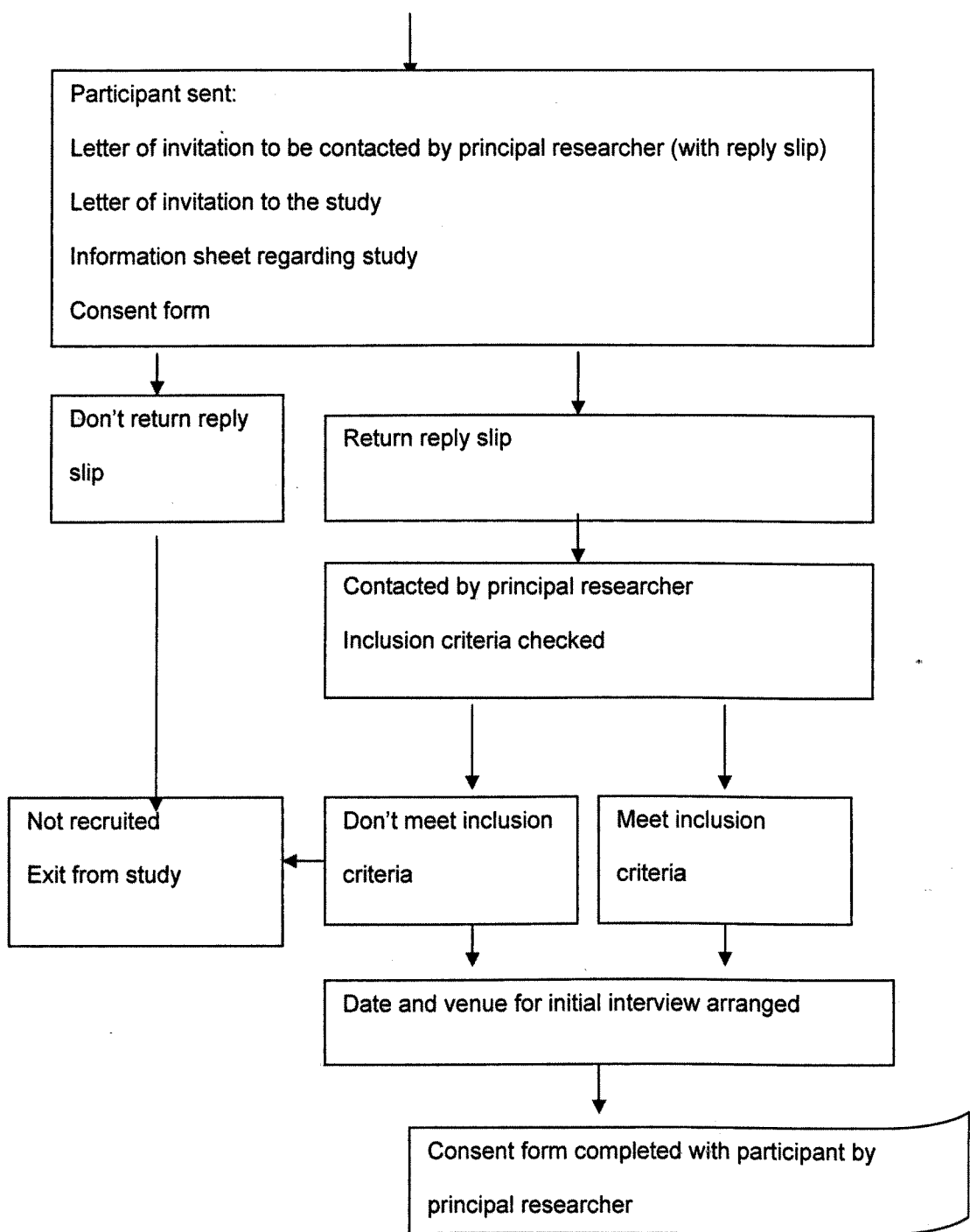
#### **4.2.4 Sample recruitment**

Initial recruitment was directly from the Rheumatology clinic, with the Consultants asking participants whether they would be amenable to me contacting them. A notice had been put into each Consultant clinic room to remind them of this but they frequently forgot and in the first 6 months only 1 participant was recruited. The process was modified and potential participants were identified by the Consultants when they read and signed their clinic letters. Individuals meeting the inclusion criteria were sent: a letter of invitation to the study from their Consultant (Appendix 3) with consent to being contacted by the principal researcher being indicated through the return of an attached reply slip (a stamped addressed envelope was included); a letter of invitation from the principal researcher (Appendix 5); a written explanation of the project (information sheet) (Appendix 6); and a consent form (Appendix 4). Following receipt of the reply slip they were contacted by the principal researcher: the nature of the study was explained, and questions and concerns considered and answered. If they still had an interest in being involved in the study a date was made for the initial interview. At the interview the project details were explained once more and the consent form completed. Verbal consent was regained at each individual phase of the study. The process of recruitment is detailed in figure 1.

Given the long time period between interviews it was decided to send the participants a card each Christmas with an update of what was happening in the study and details of any presentations that had been given. This was considered an appropriate way of trying to aid retention within the study and was also aligned with the feminist methodological principle of reciprocity that was influencing the study design.

**Figure 1 Sample recruitment**

Participant identified in Consultant Copy  
letter as meeting inclusion criteria for



#### 4.2.5 Data collection

Section 3.3.1 explored the theoretical perspectives that had influenced the choice of in-depth semi-structured interviews as an appropriate method to explore the diverse experiences of the different participants and to gain an insight in to their unique beliefs and understandings. Semi-structured interviews would allow the participants the opportunity to tell their stories within the framework of eliciting their experiences of being diagnosed and living with FMS. The theoretical and philosophical underpinnings of this design approach have been discussed in-depth in Chapter 3 and introduce the interview as both a social and symbolic interaction. Qualitative interviews are, considered a research method that “provides us with a means for exploring the points of view of our research subjects, while granting these points of view the culturally honoured status of reality” (Miller and Glassner, 2011).

Given the existence of literature that had already explored the experience of individuals with FMS (section 2.3), my own clinical experience (section 1.3) and intuition it was possible to develop an interview guide (Appendix 7) for the first interviews. This focussed on the initial thoughts I had about the illness experience for these individuals and included: their perceptions of FMS; perceptions of themselves; the effect on quality of life; how they coped with and managed their symptoms of FMS; how they had been diagnosed and the impact it had on them. Themes arising from these interviews (individually and globally) would be used to inform the second and third interviews.

Prior to the second and third interviews the content of the previous interview(s) would be summarised and described to the participants. It was not my intention to influence the content of further discussions by ‘putting words in to their mouths’ but to refresh their memories about key issues that had been discussed. I felt that this was particularly important where sensitive issues e.g. spousal abuse/child abuse might have been disclosed to ensure that they were still happy to consent to this information being included in the study. This was consistent with the principle of reciprocity.

In alignment with the epistemological foundations of the study the interviews were considered as events where both the interviewee and interviewer were active participants. Within the qualitative interview the researcher can be considered as the research 'tool': the information generated is dependent on the ability of the interviewer to facilitate disclosure by the participants and allow them to "verbalize, interact, conceptualize and remember" (Mason, 2002 p.64). As a relatively novice researcher I was concerned about my own ability to conduct the interviews adequately although this became less of an issue as the study progressed. The epistemological position adopted emphasised the interaction of researcher and researched: in order to gain access to the experiences of participants I needed to consider in detail my position and relationship with each participant within the interviews.

Previous research (Sin, 2003) has identified how the venue of a research interview can influence the data obtained. Participants would be given a choice of venue: home, a University Building or the NHS Trust. Social categories including age, race and gender together with how someone appears within their own lives are all understood to influence the information that individuals can choose to disclose about themselves in any social interaction (Grbich, 1999). It would be evident to the participants when I met them that I was a married, white British female in her thirties/forties. However, more ambiguous was my professional status. At the time of commencement I was employed as a physiotherapy lecturer/practitioner; this was a role that incorporated clinical, academic and research facets. I considered it would be unethical to deny any of these roles and therefore chose to introduce myself using my job title (physiotherapy lecturer/practitioner). However, I decided to make it explicit that I was studying part-time for a PhD and that I was interested in finding out what it was like to live with fibromyalgia: I emphasised that my role whilst visiting them was as a researcher rather than a therapist.

In order to address the research objective of whether time mediated the experience of living with FMS it was necessary to interview the participants on more than one

occasion. Interviews were to be conducted within 3 months of being diagnosed and annually for two years: this improved the potential for a more intimate research relationship to be developed between myself and the participants i.e. enhanced trust and rapport. It also provided the opportunity to revisit areas of interest as well as explore new topics that arose.

Interviews were taped on a digital recorder; audio-taping is considered (Avis, 1999) less intrusive than video recording and allows the collection of greater volumes of textual data than hand written notes. Tape recorders are considered to be an accepted part of normal day to day life with most people, once the interview is underway, forgetting that it is in use (Crabtree and Miller, 1999; Bowling, 1999). Inaccurate data is a threat to validity and the information captured on a tape recorder is only a partial representation of what took place in the interview; it was therefore combined with hand-written notes to record non-verbal interactions occurring. The audio data was transcribed verbatim in order to capture the essence of the conversation that had taken place and reduce the possibility of data recording errors (Hansen, 2006). The hand written notes that had taken place at the time of the interview would be added to this to give a more complete picture of the interaction.

After each interview reflections were made with the acknowledgement that this required considerable objectivity. They formed part of the research diary that I was to produce throughout the course of the study. These reflections included details on both how I felt the interview had proceeded (and possible areas for improvement), as well as the process and content of sampling, data collection and analysis. The role of a 'researcher's diary' is acknowledged (Grbich, 1999) as a means of demonstrating the reflexivity of the researcher within the research process and it was my intention that the recording of my reflections and self assessment would increase the transparency of this. The information within the diary would form part of the data collected and the analysis that was performed.



#### **4.2.6 Data analysis**

Chapter 3 identified how the epistemological and theoretical commitments of this study were used to underpin the methods of data analysis that were chosen within this study. Emphasis was placed on the iterative and emergent nature of the study design and the commitment to critical reflection and pragmatism. Analysis was to be embedded within every aspect of the study; it was not an isolated process but would infiltrate all aspects of the study. It would be a product of emerging data interpreted alongside my own beliefs, existing and new research literature.

Data transcription can be considered as part of the analytic process. It provides an opportunity to hear once more what was said during the interview and identify things that were said but missed during the actual interview itself. Hansen (2006 p.113) draws to our attention that even for the experienced researcher this can occur "perhaps because I was busy thinking about my questions or worried about something else". It also begins the analytic process as one begins to consider what has been said, how it has been said and the context within which it has been said (Hansen, 2006). It is acknowledged that transcription of the data can be associated with judgements made by the transcriber (Mason, 1995) and that the quality of the transcription will affect the data that are analysed. It was my intention to either transcribe the interviews myself or read transcripts whilst listening to the interview to minimise errors.

I appreciated that the transcription would never completely capture the nature of the interaction between the researched and researcher (MacLean et al, 2004). As the purpose of the study was not to perform conversational or discourse analysis, pauses and hesitations were not included in the transcription. However, to reflect better the nature of the conversation, key events in the interview e.g. someone entering the room or a participant becoming tearful, would be noted as these might have interrupted both the flow and subsequent content of the conversation.

At the commencement of the study it had been intended that data analysis would follow the principles of iterative thematic analysis to identify themes of importance within the data. Details of this have been given in section 3.3.4. This placed an emphasis on the continued movement between the processes of data collection, reading and reflecting on the data, attempting to analyse and interpret the data, and evaluating the findings in the light of existing evidence and my own knowledge/experiences. The emergent nature of the analysis, from the beginning of data collection will be described in the next section. This will then focus on the transition that took place resulting in narrative thematic analysis being adopted to provide the definitive approach taken to produce the results and their interpretation.

### **4.3 Fieldwork**

This section will describe the process of research in action i.e. what took place in this study. It is intended to make transparent the emergent and iterative nature of the design; in doing so the audit trail of sampling, data collection and analytical decisions are made visible.

#### **4.3.1 Sampling**

The period of participant recruitment took place between 2004 and 2006 with 23 participants entering the study (22 female and 1 male). The sample size was determined by the emergence of data saturation i.e. the point at which no further themes appeared to be emerging from the data (Bryman, 2004; Corbin and Strauss, 2008). All of the participants were invited to be interviewed for a second time in order to explore the longitudinal nature of the illness experience.

During the second interviews a possible theoretical model to explain the emergent findings was identified based upon quantitative research studies in the USA (Turk 2005; Turk et al, 1996). These studies suggested that patients with FMS undergoing out-patient rehabilitation programmes were not a homogenous group. In both of these studies the Multi-Dimensional Pain Inventory (MPI) was used to classify patients with

FMS and found the presence of three sub-groups with defining characteristics relative to each other. The interpersonally distressed (ID) showed, relative to the two other groups, lower levels of perceived solicitous and distraction responses from partners and spouses and higher levels of punishing responses; the adaptive copers (AC) demonstrated lower pain severity, decreased interference with every day life, less affective distress and a greater perceived level of life control and activity levels; the dysfunctional group (DYS) in contrast showed high pain severity, increased interference with every day life and affective distress and a lower perceived level of life control and activity levels.

The data was reviewed in light of Turks model (Turk, 2005; Turk et al, 1996) but failed to adequately explain the findings emerging. It appeared that there were four potential groups of participants and evidence of how this was considered presents in an excerpt from my researcher diary:

***Development of a sampling frame for third interviews 09 .10.06***

*? different sub-sets of experiences representative of the way that people are living with and interpreting this condition. People don't seem to be just be in one group all of the time. There seems to be a degree of shift between the different groups dependent on what is happening with their FMS and the rest of their lives, although they seem to have a preference for moving back to a particular group:*

***Group 1***

*Seem to be seeming managing their illness well and beginning to get their life back on track with some semblance of their previous lives (P1, 15).*

***Group 2***

*Are also showing a return to some sort of normality but this is markedly different to the lives they lived before. They are returning to a new life where their expectations and aspirations have adapted and they are actively re-engaging with life. They are seeking benefits and treatment to help them do*

*this (P1, 2, 4, 5, 6, 8, 9, 12, 14, 15, 16, 18, 19, 21). This is in contrast to group 3.*

#### *Group 3*

*Like Group 2 are living a different life but they are trying to develop a new life that involves them disengaging i.e. looking at what they can avoid doing/what benefits they can get to facilitate this (P7, 11)*

#### *Group 4*

*The fourth group (who are the typical heart sink FMS patient described by colleagues and some of the literature) are in the minority. However they seem to have lost all control of their illness and their lives and are resigned to a life of increasing misery (P3, 10, 13, 17, 20, 22)*

***Points to consider:*** *Need to sample participants that represent these different potential subgroups as I return for a third time.*

10 participants were interviewed for a third time, representing the point at which data saturation was reached.

#### **4.3.2 The semi-structured interviews**

Entering into the study participants had been offered a choice of venue where there was sufficient privacy and time to conduct the interviews: their home, the university, or the hospital. 6 of the participants (P1,2,7,12,14,19,) chose to be interviewed at the university. When the interviews were conducted at the university they took place within my office, and participants were offered a choice of seating. The majority of participants chose for the interview to take place within their home. When they chose this venue I asked, at the time of scheduling, if it was possible for us to not be disturbed. If there were third parties present (when the interview began or during the course of the interview) I confirmed that they were happy for the interview to still take place. To ensure my own safety I recorded in a diary at work my whereabouts and informed my partner of home that I would be out on a home visit with an expected time of arrival home.

As the study progressed, I was able to reflect on the potential effect of the research setting on the research relationship. I compared transcripts to ensure that it wasn't the case, but when the interview took place in my office I was always more conscious of the potential for a power relationship to be present. I was in an environment where I felt I was potentially more at ease than the participants and was conscious of trying to ensure that this was not the case.

Establishment of rapport was considered important to minimise differences in potential status and facilitate the interaction of flow of conversation (Grbich, 1999). A decision was therefore made to precede each interview with a non-recorded period of time during which the purpose of the study was reiterated, what was going to happen was described, and any questions could be asked. When the study took place at the University participants were offered a drink or if I was in their house I would accept a drink if it was offered. It was my intention that this time would help to place us both at ease prior to the interview and if participants brought up a topic that I thought was relevant to the study I would ask if I could revisit it once the recording had started or make a written note of it.

In all instances participants were advised they could stop the interview at any point if they didn't want to continue, take a comfort break or simply, to move around if they became uncomfortable. They were also informed that they did not have to discuss anything they felt uncomfortable about. This was especially relevant in this study as there was the potential for sensitive information to be disclosed e.g. abuse, and this became more apparent as the issue of relationships and personal intimacy emerged in the data. On a number of occasions participants being interviewed became tearful and interviews were suspended whilst they composed themselves. All of them chose to continue with their interviews.

When I met them for the first time many of them wanted to know whether I had any new information to give them about current advances in FMS management.<sup>9</sup> The

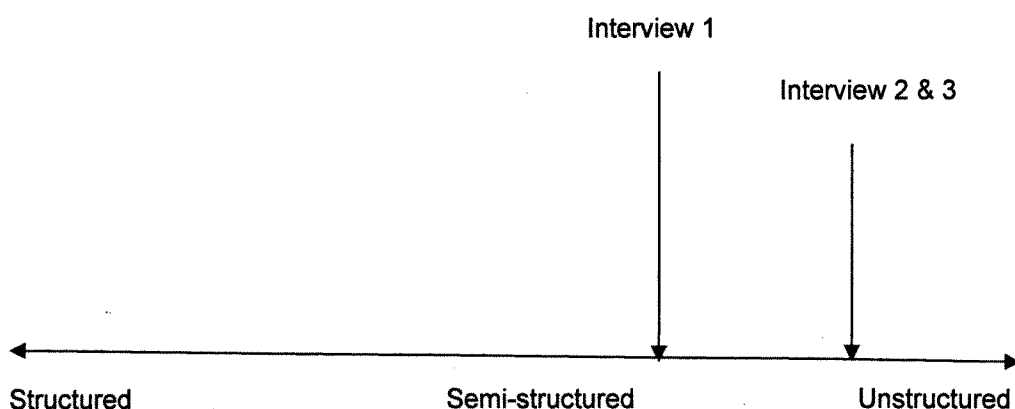
ending of each meeting and the beginning of the second and third interview always involved an element of social talk: they would want to know how I had been, about my family and how my study was going. I felt it important to share some information about myself but was conscious of the extent to which I was prepared disclose my own personal identity, and did not want to confuse participants as to the nature of the relationship between us. What I had not accounted for prior to entry to the study were tensions I would feel when issues were discussed that were personally sensitive to me; this is described in Chapter 6.

Interviews were generally brought to a close when no new issues were being discussed or occasionally when participants had limits on their time e.g. in interview 1, P9 was aware her children would be returning home from school. The interviews generally lasted from just under one hour to just over two hours. This did not however fully reflect the time I was with each participant given the social and conversational nature of the interaction: they frequently described how much they had enjoyed having someone to talk to who was interested in listening to them. On each occasion participants were debriefed and thanked for their participation. I reminded them what would happen to the data and told them that once I had written the findings up I would send them a short summary report. They were keen to be advised if and when I was successful in obtaining my PhD, and I considered that this provided evidence of the collaborative nature of the study. I agreed that I would let them know of this.

The interview guide provided some structure and in this way allowed conversation to be initiated and guided. I was especially vigilant in my attempts to ensure that the interviews did not reflect my asking questions that only I considered important.

Similarly I was mindful of the need to not correct participants if what they said was a misrepresentation of what I considered would have taken place (given my knowledge of local assessment and management practices). The interviews were approached flexibly and iteratively: a non-rigid approach was used in the ordering of questions, questions were re-phrased if necessary and new avenues were explored as they

arose. As a result the interviews were positioned further along the continuum between unstructured and structured than I had originally anticipated, with this more noticeable in the second and third interviews (see figure 2).



**Figure 2 To demonstrate the position of interviews within this study along the continuum of qualitative interviewing**

Over time the interview guides served mainly as prompts and I was increasingly receptive to the spontaneous exploration of issues emerging that had previously not been considered. This is demonstrated in this excerpt from my researcher diary following my first interview with participant 5:

***Relationships and FMS 05.04.05***

*Relationships might be an area to explore. Living with FMS and relationships with their partners may be important. There is the potential for greater physical, financial and emotional burdens to be placed upon them. The partners may need support as they also have to accommodate to the illness AND support the patients. Have failed to consider how FMS would affect intimacy and sexual relationships.*

***Points to consider/points to action:*** Add questions about relationships and their partners to the interview guide. Need to look back at the literature on

*FMS, and perhaps other chronic illnesses (esp. chronic pain) to see what if any correlation/support for this there might be there.*

A return to the literature (Paulson et al, 2003; Soderberg et al, 2003) reinforced the findings that FMS had both positive and negative impacts on relationships, both bringing partners together but also causing greater financial and physical burden, and increased social isolation. Questions regarding relationships, and how they had been affected since the onset of FMS, were added to the interview guide and followed up in the second and third interviews. I considered that the impact of time and the experience of living with FMS might further exacerbate any problems or highlight how people were working together to resolve problems.

Throughout the study critical reflection was utilised and reflected in the iterative and emergent nature of the study. As key issues arose previous data was revisited together with appropriate literature to 'test' the potential validity of the findings. This was incorporated into subsequent interviews as well as at the beginning of each stage of the study to form the basis of the next interview guide. Within the first interviews being diagnosed dominated many of the interviews, and this supported findings of earlier studies (Schaefer, 1995; Hellstrom et al, 1999; Sturge-Jacobs, 2002; Thorne, 2004) as well as my own thoughts (which had been that being diagnosed would be important to those with symptoms of FMS). This is reflected in the following excerpt from my researcher diary:

***Meaning attached to being diagnosed 17.03 .06***

*Being diagnosed appears to be a significant event in their lives and seems to be related: reassurance and knowing what's wrong, hopes and access to treatment and information, and credibility for them and their family. All of them talk about the relief that came with being diagnosed and of finally knowing what was wrong with them. For some this triggered a change in focus from finding out what was wrong with them to then searching for treatment and*



*information. Doubts and anxieties were raised about the problems of living with an invisible and contested illness with an uncertain trajectory.*

***Points to consider:*** *diagnosis seems to have both negative and positive connotations to participants and others. More credible as have diagnostic label but nature of this illness lacks credibility. Diagnosis seems to be having an impact on how they then incorporate, cope and manage. This is an area to follow up in the next interviews.*

The existing literature identified in section 2.3.1 had examined the impact and meanings attached to diagnosis at one moment in time, in individuals that had been diagnosed for varying periods of time (1-30 years). It was my belief that time might mediate what diagnosis meant to the participants, and this was one theme that informed the development of the second interview guide (Appendix 8). Other themes of importance were developed and incorporated in a similar manner and included: access to and the impact of treatment/benefits/medical consultations; impact on and the role of relationships; self-perception; quality of life; perceptions and mechanisms of coping; consideration of and planning for the future.

The third interview used a much 'looser' guide with far greater emphasis on pursuing what the participants had told me. Prior to this interview, their previous two transcripts were read and prompts written of key events or areas of interest to be followed up. I wanted to allow them to continue with the conversations that we had been having when we had last met, and not manipulate what the participants wanted to tell me. These interviews were associated with a transition in analytical approach and the consideration of the presence of illness narratives that will be described in 4.3.3.

I was conscious that it would be important to avoid 'manipulating' the interviews so that the participants only answered questions that would support my hypothesis and mindful that they needed the freedom to disclose what was important to them.

Prior to the second and third interviews the content of the previous interview had been summarised to familiarise the participants with our previous conversations and also ensure consent was still given to use the findings. None of the participants retracted or amended any of their previous statements; they highlighted how, given their poor memory, they were glad of the opportunity to refresh their minds ahead of us talking.

#### **4.3.3 Data analysis**

This section will describe in further detail how data was analysed and the evolution from iterative thematic analysis to narrative thematic analysis. The process of analysis began with transcription. The data from the interviews in this study were transcribed verbatim: 10 were done personally with the remainder done using external transcribing services. To recapture the opportunity to 'listen' to the interview again, all interviews were listened to alongside the transcription if external transcribing had been used. Transcripts were read alongside field notes in an attempt to capture those elements of the interview interaction that were not on the tape e.g. body language.

The development of the analytical approach was strongly influenced by distance from the data. This was a result of the longevity of the period of data collection and personal circumstances which; this I believe enhanced my ability to be objective and reflexive. Time away from the study was influenced by personal circumstances: this included maternity leave of one year (9 months post-registration), a change of job in 2006 and 2010, separation from my partner in 2009 and divorce in 2010. Discounting maternity leave the study took over 7 years to complete. Its' long duration (in particular the period after which data collection was completed in 2008) necessitated the continued re-familiarisation with the findings and questioning of whether the explanation I was providing was adequate. These 'absences' facilitated the 'wondering and pondering' that can be associated with qualitative data analysis providing opportunities for renewed objectivity.

#### **4.3.3.1 Iterative thematic analysis**

Data analysis in this study was initially approached utilising the perspective of iterative thematic analysis. This was neither a linear or cyclical process: the stage I was in was determined by what was emerging from, or happening within the study at any one time. This can be witnessed in an excerpt from my researcher diary after the first interview, and indicates how I was linking emergent data with potential literature and my own beliefs (analysis) whilst also considering the interaction of the interview itself (data collection):

##### ***Reflections after 1<sup>st</sup> interview 05.10.04***

*Felt this interview went well and this patient will cope/live with her condition: but WHY? The questions in the interview guide seem to have elicited some responses! I enjoyed the interaction and felt that P1 had opportunity to say what she wanted to as well as answer the questions I had. Her answers also offer some support to the existing research: she had her symptoms for some time before she asked for help (Henriksson, 1995a; Hallberg and Carlsson et al, 1998; Raymond and Brown, 2000; Sturge-Jacobs 2002); she was keen to get a diagnosis and this then meant that she could access further treatment (self resourced and provided by the NHS e.g. medication/pain management group)(Soderberg and Norberg, 1995; Soedreberg, 1999; Hallberg and Carlsson, 1998; Hallberg and Carlsson, 2000); she thought it was a condition that was stigmatised (Asbring, 2001; Asbring and Narvanen, 2002); she has described how it affects her partner as well as her (Soderberg et al , 2003; Paulson et al, 2003).*

***Points to consider:*** *need to look at more data as this is only the first interview. It is possible that there are some possible codes here: diagnosis, treatment/management, self-efficacy, clues within what patients say that symbolise those that will manage versus those that will not.*

Throughout the first interviews the initial process of coding the data with 'loose' tags took place. They were initially created from the language that the participants themselves had used: as further examples were found to either support or negate the findings the codes were refined. They were dominated by three broad areas of interest: the lives that had been lived before FMS and the aspirations they had for the future; how the symptoms of FMS had either markedly interrupted their lives or abruptly brought it to a standstill; how they had struggled for a diagnosis and what the diagnosis had meant to them. Within each of these three broad codes sub-codes were being considered that gave greater detail and understanding. This was accompanied by a continued examination of the research literature that might support or negate the coping scheme being developed. This is demonstrated in Table 4: for each code an example from the textual data is given and the presence of any supporting research literature that I had accessed at that time.

I was conscious that I had a growing interest in the experience and meanings attached to the diagnosis of this condition. This was a product of the data that was emerging, the literature I was already aware of, described in section 2.3, and my own beliefs. It was my opinion that it was at the point of diagnosis that the participants had become patients with a visible condition, FMS, as opposed to non-patients with indiscrete and invisible symptoms. Section 2.3 described how individuals with FMS consider the contested nature of the condition and the difficulties associated with diagnosis, and made apparent what this might mean to patients. The emergence of findings that corroborated the existing knowledge and reinforced my own beliefs seemed significant and is evidenced in the presentation I gave of these findings at the World Congress of Physical Therapists in Vancouver in 2007: the abstract summarising this is given in Appendix 9. The presentation of these findings aligned with my pragmatic

**Table 4 To demonstrate development of coding scheme after first interviews**

Main 'code'	Sub-'code'	Textual example	Literature
Life before FMS	A normal life	"Before FMS I was like everyone else. Went to work, sorted the house, sorted the kids, it was just normal" P9	There was no evidence of any literature regarding life before FMS at this stage of the study
	A predictable life	"You know before you normally knew if you wanted to do something tomorrow or next week you could" P14	
	Normal response to illness	"Normally when you get ill you take something, see the Dr 'it's a virus!' and you get better" P20	
	A planned past, present and future	"Life wasn't always as you'd hoped but generally what you wanted to happen, happened" P16	
An interrupted life	The onset of symptoms	"These pains and tiredness came from nowhere and stopped you in your tracks" P18	Raymond & Brown, 2000; Hellstrom et al, 1999; Hallberg and Carlsson, 2000

	Noticing something was wrong	"And you rested, took painkillers, saw the Dr but nothing helped. It wasn't right" P14	
	Needing help to carry on	"And you become more reliant on others to help. Someone to help with the housework and sometimes a shoulder to cry on to get you through" P15	Soderberg et al, 2003
	No longer the same person	"I'd been fit and active, exercised, worked, looked after the house. But now I'm just lazy, I can't do those things" P18	Asbring, 2001; Asbring and Narvanen, 2002; Paulson et al, 2002.
	The impact on relationships	"..and he didn't understand, I wasn't the same person, he couldn't understand what was happening" P13	Soderberg et al, 2003; Paulson et al, 2003
Diagnosis	The struggle for a diagnosis	"There was anger that I'd been made to wait so long, that it was in me head, that it was me" P3	Schaefer, 1995; Hellstrom et al, 1999
	Meanings attached to diagnosis	"That's what made me feel good, knowing that it's not all in me head" P8	Schaefer, 1995; Hellstrom et al, 1999; Kelly and Clifford, 1997; Raymond and Brown, 2000
	Being able to	"I couldn't afford things like an electric can opener so I could open a can.	Soderberg et al, 1999; Soderberg and

	access help	But I can now because I've got the DLA" P11	Norberg 1995; Hallsberg and Carlsson, 1998; Hallberg and Carlsson, 2000
	A known but uncertain future	"The leaflet (ARC leaflet)has helped me know what's wrong but the only thing I really know is that no-one knows whether I'll get better or worse" P23	

epistemological stance and the belief that findings should make a practicable difference.

Initially the second interviews saw a continued development and re-modelling of the codes as new areas of potential interest arose, and the process of identifying textual data and other supporting evidence continued. This resulted in 5 broad codes being decided upon: life before FMS; being diagnosed; the experience of symptoms; living with FMS; managing FMS. There were sub-codes, which were linked within each broad code, and gave greater detail and depth to the main code. At this stage the focus of the analytic process still remained on description rather than the development of theoretical understanding and continued to reflect most of the existing literature on either FMS or other contested conditions. In contrast to previous studies interview data was contemporaneous and participants did not have to recall events that had happened some time ago. However, I was concerned that I was failing to make the transition from description to explanation and theory generation.

When conducting the interviews and following this up with re-reading and/or listening to interview transcripts I was aware I was making decisions regarding how these individuals were going to cope and manage their symptoms. I considered this was linked to my role as a practitioner, when I would frequently consider after a consultation the potential outcome of treatment. The descriptive analysis was identifying experiences that were common to all of the individuals e.g. the unexplained onset of the symptoms, being diagnosed, the symptoms of FMS and the unpredictable nature of the condition. However, within these experiences it was possible to recognise similarities amongst sub-groups of individuals with respect to how they appeared to perceive and interpret their experiences, and how they were managing to integrate them in to their lives.

In section 4.3.1 I described how the potential for sub-grouping was being considered as I attempted to move towards the development of a theoretical explanation. This



was initially supported by the identification of research literature (Turk, 2005; Turk et al, 1996) that offered some empirical evidence that FMS was not a homogenous condition. However, the findings of Turk (2005) and Turk et al (1996) failed to provide an adequate theoretical explanation for the data emerging within this study for a number of reasons:

1. There appeared to be marked differences in the self reported levels of physical functioning of the participants in this study in contrast to Turk et al (1996) where levels of physical functioning were similar.
2. The descriptions of the clustering groups described by Turk et al (1996) did not adequately describe the groups I was identifying within this study (Section 4.3.1)
3. The sub-grouping reflected some of the differing characteristics of the individuals with FMS BUT did not adequately explain their experience of living with the condition. It failed to satisfactorily contextualise these characteristics within the individuals own lives.
4. Participants rarely seemed to belong exclusively to one group. At the beginning of the study all of the participants appeared to demonstrate characteristics of the AC group. With persistence or worsening of symptoms and the continued lack of a diagnosis they demonstrated a movement towards demonstrating characteristics of the DYS/ID groups. It was only after diagnosis that they showed movement into sub-groups that dominated throughout the remainder of the study. This though was not static and movement back into the other groups occurred and appeared to be influenced by other events in their (or significant others) lives.

It was these third and fourth differences that particularly challenged the usefulness of this model in explaining the findings of this study. I attempted to expand the sub-groupings (as described in section 4.3.1) but continued to feel that this was inadequate and that a better explanation should be possible. Whilst continuing to review the literature surrounding FMS and other chronic/contested conditions (prior to

the third interviews) I discovered a paper (Whitehead,2005) that facilitated a movement to narrative analysis and offered a potentially useful theoretical model.

#### **4.3.3.2 Narrative analysis**

The previous section has demonstrated how in an attempt to move from pure descriptive analysis to interpretation I was struggling to find a satisfactory explanatory model. Whilst there was data and previous research that would support the perspectives of diagnosis and coping, it was failing to integrate these findings to explain the temporal nature of the illness experience of FMS or provide a useful model that might help clinicians in the assessment and management of this condition. 'Discovery' of research that had adopted both a potentially useful analytical approach and explanatory model, warranted further investigation as to its applicability to this study.

Whitehead (2006) reported the findings of a longitudinal qualitative study that utilised illness narratives and the typologies described by Frank (1995) to explain how individuals with chronic fatigue syndrome describe and interpret their illness experience. This study shared similarities with my own in that it was exploring the illness experience of a contested and unpredictable condition and was utilising qualitative interviews with principles of qualitative analysis rather than a set method. In contrast: it had a methodological commitment to hermeneutic phenomenology, had recruited patients at varying time points since diagnosis (1-8 years), and data collected during interviews was reliant on retrospective reporting on events that had happened up to 32 years ago. The findings and methodological commitments of this study resonated with my own beliefs of what was emerging from the data and led me to examine the potential usefulness of both illness narratives and Franks' (1995) narrative typologies. This influenced the results that are reported in Chapter 5. Narrative research is characterized "as providing a method for "telling stories", giving voice to those traditionally marginalized, and providing a less exploitative research method than other modes" (Hendry, 2007 p.489). It is acknowledged (Overcash, 2003)

that narrative research itself can encompass a description of the type of data that is collected, a method that is employed or an approach to data analysis. Narratives imply chronology and temporal sequencing of events with stories that whilst sharing a common plot also show evidence of a beginning, middle and end (Christer-Hyden, 1997).

Illness narratives are considered the stories that individuals tell to make visible their illness experiences to others and are dependent on the context within which they are generated. In his book "The illness narratives" Kleinman (1988) describes how the illness narrative is not merely recounting of the illness experience and events that took place but the individuals perception and ordering of this, and reflects how the individual is interpreting this within their unique personal and social context: "The illness narrative is a story the patient tells, and significant others retell to give coherence to the distinctive event and long-term course of suffering. The plot lines, the core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings" (Kleinman, 1988 p.49)

It had not been the original intention of this study to use a narrative approach but on reflection I considered that the temporal nature of this study was providing a unique opportunity to capture data that reflected this. This was also facilitated by the nature and social interaction of the interviews taking place. The collaborative nature of the interview was allowing the participants to recount what had happened in their own words and in the order in which they wished to disclose information. This contrasted with narrative approaches that "start people off by asking them to tell their story about an event" (Bryman, 2004 p.413) but I felt that the use of questions had facilitated the flow of conversation and disclosure of what was important to the individual rather than a strict ordering of questions to be followed.

Narrative analysis is considered to be concerned with "the connections in peoples accounts of past, present and future events and states of affairs; people's sense of their place within those events and states of affairs; the stories they generate about them; and the significance of context for the unfolding of events and people's sense of role within them" (Bryman, 2004 p.412). It is concerned with analysis of the data as a whole and consideration of how the data itself is constructed by those producing it. The research question posed by this study was "what are the experiences of individuals diagnosed with FMS and do they change over time?" Due to its nature the question itself had led to the emergence of data that had a temporal nature, and the potential emergence of a narrative within it. I was however, increasingly conscious that given the duration of this study, the true 'end' of the illness experience for these individuals would remain undiscovered within the limits of this study.

Narrative analysis is considered to encompass different approaches that include thematic analysis, structural analysis, interactional analysis and performative analysis (Bryman, 2004). I considered that I was most concerned with what was being said by the participants as opposed to how it was said or the co-construction of meaning. Thematic analysis would allow for the systematic identification of themes within the data that would support the development of the narrative that was being used to describe it. The use of thematic analysis offered the potential to consider how the themes I had been developing contributed to a main narrative, and answer the questions I had been struggling with of how to make sense of the potential sub-grouping of experiences.

In this instance thematic analysis would be utilised in two ways (Overcash, 2003). Intra-thematic analysis would allow me to consider the themes that were unique to individual participants, whilst inter-thematic analysis would allow me to consider themes that were common amongst the participants. This allowed me the opportunity to contemplate the emergence of a core narrative(s) shared by the participants, whilst at the same time retain the uniqueness of their stories. I considered that this might

provide me with an opportunity to find a solution to the difficulties I had been having in resolving how to explain the movement between sub-groups that the participants had been demonstrating.

Within the last three decades there has been a growing body of research utilising narratives to re-engage with the individuals' subjective account of their illness (Hansen, 2006; Bury, 1982 ; Charmaz, 1983 ; Williams 1984). This has been associated with a resurgence of both chronic illness and a growing elderly population necessitating reconsideration of the biomedical model with its' emphasis on treatment and cure. The emergence of the bio-psychosocial model (Engel, 1977) has reignited the need to engage once more with an individuals' experience of their illness, and attempt to understand this in the context of their lives and their individual system of beliefs. I was now able to consider this in light of my own belief that there needed to be more explicit understanding of the lived experience of FMS and that the use of illness narratives might facilitate this.

#### **4.3.3.3 Franks' narrative typologies**

In his book 'The Wounded Storyteller' Frank (1995) utilises the conversations with his own patients, together with his own experiences (of having had cancer), to develop a theoretical model that proposes the existence of three types of illness narrative. The model does not deny the individual experience of living with illness but suggests (Frank, 1995) that each individual story potentially shares a common theme or 'plot' that distinguishes it from others. It is intended (Frank, 1995 p.76) that recognition of these shared characteristics will "encourage closer attention to the stories ill persons tell; ultimately, to aid listening to the ill".

Previous attempts at sub-grouping participants had failed to provide a satisfactory explanation of the findings. I began to consider that the participants were telling 'stories' that had core characteristics, and that rather than attempting to sub-group the participants I should be clustering their stories. I wondered if it might be possible to

develop a theoretical model that could be used by clinicians to recognise how individuals were living with, and interpreting the impact of, FMS based on this sub-clustering. If clinicians were able to recognise the 'clues' or 'themes' within conversations that they had with patients with FMS, they might be better able to understand the illness experience according to the different narratives being described.

Frank(1995) advocates that individuals with illnesses: do not necessarily adhere to the same 'plot', that the presence of a particular plot shows no temporal relationship, and that the movement into different narrative types is influenced by the context within which the illness is being experienced at any one time. This was also reflecting my own thoughts that the emergent data was suggesting participants belonged to different groups with unique and characteristic differences in their illness experiences. I had been unable to explain how participants could belong to more than one group which had led me to question whether the characteristics and sub-groupings were correct. At other times they appeared to move between groups albeit for varying periods of time. Franks' findings (1995) encouraged me to examine in greater depth the data I had collected and to consider an alternative explanation for my findings.

The narrative typologies described by Frank (1995 p.76) are Quest, Chaos and Restitution and each has characteristics that distinguishes it from the others. The restitution narrative is the dominant story told when people are acutely ill and is characterised by the plot of "Yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again" (Frank, 1995 p.77). This demonstrates alignment with the biomedical model with the emphasis placed on the medical or health care practitioner to identify objective signs and symptoms of illness, reduce these to a diagnosis and then implement appropriate treatment that would lead to a cure. It also resonates with the sick role (Parsons, 1951): this recognises the expectation that the doctor will implement the appropriate remedy to cure the sick and that the patient, who is

absolved from normal societal obligations will want to get well, seek help and engage with the cure that is offered.

I believed that the restitution model might provide a useful explanation for findings that were emerging from this study. The restitution narrative was consistent with the assessment and management of FMS being primarily centred within a biomedical paradigm: this was being delivered by health care professionals and expected by those experiencing the symptoms of FMS. This was most noticeable in the early interviews and discussions surrounding the participants' experience of FMS but also in past recollections of illness.

In contrast the chaos plotline describes a story where control has been lost and "imagines life never getting better" (Frank, 1995 p.97). Where chaos is prevalent individuals are "sucked into the undertow of illness" (Frank, 1995 p.115). There is an acknowledgement (Frank, 1995) that these stories are difficult to hear and are characterised by their lack of order and often distressing nature. Yet it may be in the telling of such stories that these individuals and their experiences might be able to be acknowledged and in doing so the opportunity for re-evaluation and change presented.

It was my belief that this plotline might share characteristics with the 'heart sink' patients considered by colleagues and some research literature (Erllich, 2003; Hadler, 2003) to exemplify those with FMS. My own experience of interviews that shared common features with this narrative was that of difficulty staying within the interview. This seemed to be a result of the unstructured nature of the interview but also of the despondency contained within it. This is reflected within the following excerpt from my researcher diary after interview 2 with participant 13:

**Participant 13: Reflection after interview 2 05.08.06**

*This is the second interview with P13 and like the first interview we had I have come away feeling drained. With other interviews you can feel almost euphoric. I wonder if it's that intuitive feeling you get about how they are going to get on, how they are going to do in the long run. And I wonder if this is associated once more with the practitioner side of me. I want people to do well, to get better. There's something innately satisfying about the thought that someone has taken control of their problem and is doing something about it. With her this loss of control is evident in other aspects of her life.*

**Points to consider:** *It is tempting to disengage with people like this who are not even in the pre-contemplative stage of the readiness for change model. I need to embrace listening to all of the experiences. They all have a right to be heard. Need to make sure I don't 'rush them along and make sure I don't spend extra time with those whose conversations I am enjoying.*

Quest represents the final plot-line and in contrast to chaos embraces the concept that life will never be the same. When individuals are telling quest stories it is suggested that they are "searching for alternative ways of being ill" (Frank, 1995 p.117): the dominant voice within the story is that of the ill person as they take control of their illness and identify ways to use it. There is an acknowledgement that narrators of quest stories are frequently seen as 'heroes': individuals demonstrating how they have been able to overcome adversity and rise to the challenges posed by their illness.

The quest narrative reflected a story line common to many of the patients with chronic conditions e.g. osteoarthritis and low back pain, that I encountered within my normal clinical practice. These narratives were familiar and reflected those that, in hindsight, as a practitioner I most enjoyed. The research literature (Goldenberg, 2004) and my own clinical practice had acknowledged the treatment efficacy of strategies that helped some individuals with FMS to manage their symptoms, although cure remained elusive. I had therefore expected to encounter recollections of where individuals were



managing to achieve this integration of their illness in to their lives when interviewing the participants within this study. I considered that the findings emerging from this study were potentially supporting the presence of this narrative typology but needed to re-examine the data to 'test' and potentially refine this new hypothesis.

I also considered it necessary to explore whether studies, other than that performed by Whitehead (2006), had utilised the same narrative typologies to explain their findings. A return to the research literature identified 4 further studies which are summarised, together with the study by Whitehead (2006) in table 5. Three of the studies Travers and Lawler (2008), Reynolds and Vivat (2006) and Whitehead (2006) had used narrative enquiry to explore the experiences of patients with CFS, a contested condition like FMS. The small sample size of the study threatens considerably the reliability and validity of the findings of the study conducted by Reynolds and Vivat (2006) but does reflect the case study design utilised.

Whitehead (2006) identified how individuals who have been diagnosed with FMS describe the three narratives described by Frank (1995) and suggested that these are temporal in nature. Initially the restitution narrative is told when symptoms are acute and resolution is anticipated. When resolution and a return to normal failed to occur, chaos became the dominant narrative. This was then followed with movement by the majority into a quest narrative as they embraced changes in identity and lifestyle to incorporate the illness in to their lives.

Study	Method	Sample	Key findings/themes	Limitations
Reynolds & Vivat, 2006	Qualitative method. In-depth semi-structured interviews with focus on self and illness. Case study design Transcribed verbatim Methods based analysis influenced by iteration	N=3 Female CFS/ME Age: 51,60,62 years Recruited via adverts in arts magazines UK	Individuals showed 3 distinct narratives demonstrating relationship between self, art and illness. No clear chaos narrative; no evidence of restitution narrative. 1 clear quest narrative with journey into more fulfilling life. Other quest story was journey into psyche and finding meaning. 3 <sup>rd</sup> narrative showed closest correlation with chaos but was	Lack of diagnostic criteria for CFS/ME threatens validity. Secondary validation of findings between 2 authors. Lack of evidence of data saturation threatens reliability and validity of findings. Lack of evidence of how data analysis emerged given its iterative nature. Little evidence of

			concerned with stasis	reflexivity  Unclear as to why these 3 participants recruited
Travers & Lawler, 2008	<p>Qualitative method</p> <p>Grounded theory</p> <p>Semi-structured interviews with focus on illness, self and CFS</p> <p>Analysed with narrative analysis and grounded theory methods</p> <p>Transcribed verbatim</p>	<p>N=23 recruited; n= 19 participated. n=16 had CFS; n= 3 recovered from CFS</p> <p>N=14 female; n= 5 male.</p> <p>Age 20-75 years</p> <p>Recruited via CFS newsletter, specialist CFS clinic and snowballing</p> <p>Diagnosis of CFS previously from a</p>	<p>3 key themes:</p> <ul style="list-style-type: none"> <li>• Violated Self consistent with chaos</li> <li>• Reconstructing Response consistent with Quest</li> <li>• Guardian response represents a movement from chaos to quest</li> </ul>	<p>Self-reported diagnosis threatens reliability and validity.</p> <p>No evidence of secondary validation of findings.</p> <p>No evidence of reflexivity</p> <p>Difficult to sometimes make sense of organization of themes which appear to be condensed to Guardian</p>

		<p>medical practitioner</p> <p>Australia</p>	<p>No evidence of restitution other than initially.</p> <p>Continual shift between chaos and quest.</p>	<p>Response,</p> <p>Reconstructing Response and Violation of Self.</p> <p>Generalisability influenced by sample ethnicity and social background e.g. white Caucasian an generally well educated and long symptom duration</p>
Whitehead, 2006	<p>Qualitative method</p> <p>Hermeneutic phenomenology</p> <p>influenced by Gadamer</p> <p>In-depth interviews on</p>	<p>N=17</p> <p>N=6 male; n=11 female</p> <p>Age 13-63 years</p> <p>Recruited from CFS clinic and support group</p>	<p>All 3 narratives (Frank, 1995) represented: quest, chaos and restitution (2 revealed restitution and chaos only)</p>	<p>Highlights role of pre-understandings but reflexivity not demonstrated in findings.</p>

	<p>up to 3 occasions:</p> <p>focus on onset symptoms and illness experience to present day</p> <p>Narrative and thematic analysis</p>	<p>and snowballing</p> <p>UK</p>	<p>Began with restitution.</p> <p>Movement then into chaos with relapses and other major life events showing a return to chaos.</p> <p>Then a movement to predominantly quest narratives</p>	<p>No evidence of data saturation</p> <p>Evidence of a theoretical/conceptual framework but does not highlight how prior knowledge is integrated with emergent findings.</p> <p>Poor demonstration of findings e.g. different narrative types merged in results</p>
Thomas-Maclean, 2004	<p>Qualitative methods</p> <p>Narrative and Phenomenological enquiry</p>	<p>N=5 focus groups</p> <p>N=12 interviews</p> <p>Female</p> <p>Age 42-77 years</p>	<p>Franks 3 narratives – quest, chaos and restitution- identified.</p> <p>Proposes reconstruction</p>	<p>Not stated where sample recruited from</p> <p>Wide duration of illness and treatment may</p>

	<p>Focus groups to then inform in-depth interviews.</p> <p>Transcribed verbatim</p> <p>Published data from 1<sup>st</sup> interviews only</p>	<p>Diagnosis (1-24years) and treatment of breast cancer (treatment varied)</p> <p>Canada</p>	<p>rather than restitution as plotline for patients who will 'never be the same'.</p> <p>Suggests true quest only evident in 3 cases, with partial representation in 3 other cases.</p> <p>Identifies presence of memoir and manifesto sub-plots of quest.</p> <p>Highlights intermittent presence of chaos narratives in stories of participants reflecting bodily difficulties and presence of other people</p>	<p>influence generalisability and reliability of findings</p> <p>Little evidence of reflexivity</p> <p>Participants are inconsistently identified against quotes making it difficult to identify their stories</p> <p>Sample had declined reconstructive surgery influencing validity with potential lack of preference for restitution</p>
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			in their lives Highlights absence of any plotline in 1 case.	
Ezzy, 2000	Mixed methods study  In-depth interviews with focus on: employment history, illness experience, religious beliefs and understandings of the future  Narrative analysis	Recruited through  national survey of individuals with HIV/AIDS  N=46: n= female (7 heterosexual, 1 lesbian); n=male (33 homosexual, 3 bisexual, 1 heterosexual)  Age 25-62 years  Australia	Linear restitution  narratives: showed an attempt to live a normal life and orientation towards the future  Linear chaos narratives: showed depression, anger, isolation and social dislocation. Typified by empty present, bleak future and idealized past life.  Polyphonic narratives:	No evidence of reflexivity.  Inconsistency in how purposive sampling demonstrated within the data  Whilst subjects recruited from survey unclear as to why 'these' subjects were chosen  Strong emphasis on polyphonic narratives at

			showed 'many voices' with contradictions and tensions. Acceptance of mortality and focus on present.	expense of other narratives. Elements of quest memoir narratives evident but not identified in analysis
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**Table 5 Critique of research studies utilising Franks' model of Quest, Chaos and Restitution**



Reynolds and Vivat (2006) failed to identify the presence of either a restitution or chaos narrative within their data and suggested that this might in part be due to the long duration of the illness experience for their subjects (>16 years). It was proposed that two of the participants told narratives consistent with quest and suggested that these differed: one was indicative of a struggle to achieve psychological resolution and understanding of the impact of CFS, in contrast to the other narrative that was more consistent with quest as described by Frank (1995) where illness was overcome and there was re-engagement with a purposeful and fulfilling life. There was some suggestion that one of the participants was in stasis, where there was a resignation to life as it was, and this showed the closest correlation with chaos.

The restitution narrative is briefly described by Travers and Lawler (2008) although critique of their paper does suggest some evidence of restitution within the narratives. They highlight how the contested nature of the condition was associated with the "failure to meet societal expectations, including the expectation that illness was biologically demonstrable" and that "participants searched (for a time) to find the trigger, behaviour or unresolved conflict underlying their illness" (Travers and Lawler, 2008 p.319). They do identify evidence of both the quest and chaos narratives and highlighted the continued movement between these two stories. Chaos was considered a response to the contestability of the condition with quest, and the movement in to this narrative, being associated with reclaiming aspects of a previous identity and recreation of a new self.

The two additional studies Ezzy (2000) and Thomas-Maclean (2004) had researched HIV and breast cancer respectively utilising narratives and Franks' narrative typologies (Frank, 1995). These two conditions differ from both FMS and CFS in that they are conditions with uncontested medical diagnoses and they can threaten an individuals' mortality. Whilst breast cancer can be associated with disease abolition, I would suggest that restitution can never be fully enacted where surgery has been performed. In contrast the advanced pharmaceutical management of HIV has meant that many

now live with what could be considered an incurable chronic condition. Both breast cancer and HIV can, like FMS, be associated with issues surrounding identity and stigma, offering the possibility for some commonalities in their illness experiences.

Ezzy (2000) identified the presence of three narrative types: two were characterised as being linear, and showing shared characteristics with the restitution and chaos narratives described by Frank (1995), whilst the third was a polyphonic narrative. Linear narratives were considered to emphasise the future that itself was the product of human action. The linear restitution narrative was typified by the desire to enact a long and normal life, and confidence in how long they could live given medical developments. The linear chaos narrative was characterised by the loss of a planned life both in the present and future, irrespective of what advancements in medical technology might have to offer. Both of these narratives were in contrast to the polyphonic narrative that was situated in the present and assumed an unpredictable future. This narrative embraced the tragedies and triumphs of living with HIV that together reinforced the unpredictable prognosis of the condition, causing subjects to place their emphasis on living in the present rather than contemplate the possible configurations of the future.

In her study of women with breast cancer Maclean (2004) identified that individuals are rarely situated within one narrative, and that movement between the different narrative types was related to the individuals' experiences. This resembles Frank's description of how narratives "are like patterns in a kaleidoscope: for a moment the different colours are given one specific form, the tube shifts and another form emerges" (1995 p.76). The individuals in this study (Maclean, 2004) showed a preference for telling the restitution narrative but it was suggested that reconstruction might be a more appropriate title for this plot given the women's inability to return to the bodies they once were following surgery. The chaos narrative interrupted when subjects were consumed by their illness and the events taking place, including diagnosis, treatment and telling other people about their condition. Movement to quest

for this group was less defined with only three participants being considered as demonstrating true quest and four others partial quest narratives. Many of the subjects did however highlight the presence of quest narratives in the media. They advocated the need to hear chaos narratives to provide a more true understanding of what it was like to live with breast cancer.

The 'model' of quest, chaos and restitution that had been applied to other chronic illnesses reflected the findings that were emerging from this study. Each narrative typology had core characteristics that appeared to be evident within the data being generated by those with FMS. However, it was evident that the application of this 'model' could allow for the recognition that whilst the characteristics of an individuals story might be context dependent i.e. heterogenous, the shared 'plot' could remain the same, i.e. be homogenous.

In accordance with this the data were revisited and tested against the emerging hypothesis i.e. the presence of these three narrative typologies. Temporal sequencing was evidenced and within each 'plot' it was possible to identify 'sub-plots' or themes that themselves reflected the experiences of those telling the main 'plot'. This reflected a transition to using the approach of narrative thematic analysis prior to the third interviews.

#### **4.4 Conclusion**

This chapter has detailed the research methods that were employed in the conduct of this study and demonstrated how these have been aligned with the epistemological and methodological commitments of the study described in Chapter 3. Emphasis has been placed on the temporal nature of the study, and its emergent and iterative nature which resulted in the application of narrative analysis. Discussion has taken place of how this was influenced by both personal and design considerations. The use of critical reflection has been highlighted in order to increase the transparency within both data collection and analysis. This has been done in an attempt to increase the

rigor and validity of the study and address my own criticism of qualitative research i.e. that it can sometimes fail to adequately demonstrate to the 'outsider' how questions regarding data collection and analysis arose and were answered.

This chapter has identified how the narrative approach emerged as an appropriate analytical model during the course of the study. The recognition of illness narrative typologies described by Frank (1995) as quest, chaos and restitution and their potential application to the data from this study were introduced. The following chapter will present the results of the findings from the narrative thematic analysis utilising the explanatory model of "Quest, chaos and restitution".

## **CHAPTER 5**

### **THE RESULTS**

#### **5.1 Introduction**

The aim of this chapter is to present the results of this study and demonstrate how they answer the research question “what are the experiences of individuals with FMS and do they change over time?” Evidence will be provided of how the following research objectives were met:

- To identify and recruit individuals newly diagnosed with FMS by a Rheumatology Consultant in a Secondary Care Setting
- to explore whether time mediated the experiences of diagnosis and living with FMS
- to identify what if any meanings could be inferred from their experiences
- to develop a theoretical model to explain the lived experience of individuals with FMS that might facilitate their holistic assessment and management by clinicians

Chapter 4 presented the results of sampling and the data collection methods that informed the study and highlighted how both of these processes were informed by ongoing analysis. This reflected the iterative nature of the study. The results presented are a further example of this and demonstrate the shift in analysis from an interpretive thematic to narrative approach that was discussed in section 4.5.3.

Section 4.5.4 introduced the narrative typologies described by Frank (1995) of ‘quest, chaos and restitution’. The primary aim of this chapter is to demonstrate how their exploration led, through a process of induction, to the development of an explanatory model that provided evidence of how these illness narratives are used to portray the experience of living with FMS. I will highlight how Frank’s model was refined leading to the development of two sub-plots within the quest narrative: active engagement and active disengagement.

In this chapter I will demonstrate how these narratives appear to manifest themselves in this group of individuals with FMS. I will attempt to highlight how the different narratives are evidenced in the stories told by individuals living with FMS. Due to the inherent nature of illness narratives and the ongoing and uncertain future of living with FMS, this analysis purports to only be a representation of the illness experience of these individuals at the time of the study. It is possible that following the interviews these narratives have been further reconstructed by the participants, and that in fact the process of the study may have contributed to this.

The adoption of thematic narrative analysis was used to evidence that within each narrative typology there were themes and sub-themes which provided further evidence of the presence of the particular plot-line. These are detailed in table 6. and they are used to present cues that indicate which narrative preference is being witnessed. At each level of the coding scheme textual data generated within the transcripts was identified to test the developing hypotheses. As the coding scheme was being developed notes were also made in the researcher diary. This detailed my own thoughts and highlighted links to potential and existing literature that might offer further validation of both the analytical process and results.

My position as a practitioner/researcher played a significant role throughout the study. It has been suggested (Freshwater and Avis, 2004 p.11) that it is not possible to disentangle evidence, beliefs and practice and "that it is the individual that is the instrument for generating evidence". I have previously described (Chapter 3 and 4) how the theoretical and philosophical perspectives of this study had led me to consider that the method of data collection adopted was collaborative, a product of the interaction between the researcher (myself) and the researched (the participants). Chapter 6 will consider the analysis of this in some detail.

Prior to presentation of the results an introduction to the 23 participants will be given. Throughout the study they will be referred to by the code designated to them.

**Table 6 to show dominant narratives, themes and sub-themes within findings**

<b>Dominant narrative</b>	<b>Theme</b>	<b>Sub-theme</b>
<b>Restitution</b> 'Yesterday my body was reliable and responsive, today it is not, but tomorrow it will be once more' 'Yesterday my life was ordinary and predictable, today it is not, but tomorrow it will be once more'	<b>An ordinary Life</b>	<b>A reliable and responsive body</b>
		<b>Every day is normal</b>
		<b>A rational explanation</b>
		<b>In search of a diagnosis</b>
	<b>Knowing what is wrong</b>	<b>The significance of a diagnosis</b>
		<b>Hope of finding a cure</b>
	<b>Daily living with an invisible illness</b>	<b>Trying to make visible the invisible</b>
		<b>For every illness there is a remedy</b>
		<b>Loss of contingency</b>
<b>Chaos</b> 'Life and the body is never going to get better' 'Life and the body is out of control'	<b>The battle to be diagnosed</b>	
	<b>Living with uncertainty</b>	<b>The limitations of a label</b>
		<b>There is no remedy</b>
		<b>An unpredictable and unresponsive body</b>
		<b>A life out of control</b>
	<b>Changing visibility</b>	<b>No-one to listen</b>
		<b>Stigma and identity</b>
<b>Quest</b> 'Life is forever changed' 'Life is tolerable' 'An alternative way of being' 2 dominant sub-plots: active engagement and active dis-engagement	<b>The need for change</b>	<b>Diagnosis as enabler</b>
		<b>Actively re-engaging with life</b>
		<b>Actively dis-engaging with life</b>
	<b>Living an acceptable life</b>	<b>Acceptance of contingency</b>
		<b>Understanding what helps</b>
		<b>The desire for quest stories</b>
		<b>A considered self</b>
		<b>Illness as a positive life event</b>

## **5.2 The study participants**

23 participants were recruited to the study: 22 male and 1 female. This reflected the point at which data saturation was reached. 1 participant died (participant 6) during the course of the study. The age range of participants was 25-71 years (mean 49 years). The time from symptom onset to diagnosis was 0.5-5 years. The information in table 7 details a brief description of each participant with the aim of helping to contextualise the individuals experience and describe the sample to assist in transferability comparisons.

19 participants were interviewed for a second time. The others failed to either make appointments (P3, 22) or keep appointments (P2, 23). 10 participants were interviewed for a third time. Each time data collection was suspended with attainment of data saturation. One participant (P6) died during the course of the study from cardiac causes.

## **5.3 Quest, chaos and restitution: the experiences of individuals newly diagnosed with FMS**

Having an illness is not just about the symptoms experienced but how these symptoms are interpreted by the patients who have them. Illness narratives are acknowledged as the stories that people tell to make public their subjective experience of illness. The chronic illness trajectory model (Soundy et al, 2010) suggests that illness narratives can provide patients with the opportunity to come to terms with changed identity. This can assist health care practitioners in understanding the goals and aspirations of patients, and help to empower them.

The results of this study suggest that the participants of this study demonstrated how illness stories of 'quest, chaos and restitution' (Frank, 1995) are utilised by individuals with FMS to give voice to the effect that the symptoms experienced have on them, their bodies and their lives. Their experience of being diagnosed and living with FMS



Participant code	Age	Time to diagnosis (years)	Employed at diagnosis (Y=Yes; N=No)	Parent (Y= Yes; N=No)	Social circumstances	2 <sup>nd</sup> interview (Y=Yes; N=No)	3 <sup>rd</sup> Interview (Y= Yes; N=No)	Interview venue U=University H= Home
P1	33	0.5	Y	N	Lived with partner	Y	Y	U
P2	45	2	N	Y	Lived with partners and 2 children	N	N	U
P3	41	2.5	N	Y	Divorced. Lived with 1 daughter	N	N	H
P4	61	1	N	Y	Lived with disabled husband	Y	Y	H
P5	37	1.5	N	Y	Lived with	Y	Y	H

					husband and 2 children.			
P6	61	4	Y	Y	Lived with wife	Y	Deceased	H
P7	59	3	N	Y	Lived with disabled husband	Y	Y	U
P8	50	2-3	N	Y	Lived with husband	Y	N	H
P9	44	4	Y	Y	Widowed. Lives with 3 children	Y	N	H
P10	62	4	N	Y	Divorced. Lived with 1 son.	Y	N	H
P11	58	5	N	Y	Divorce. Lived alone	Y	Y	H
P12	71	4	N	Y	Lived alone.	Y	N	H

					Widowed.			
P13	45	2	N	Y	Lived alone. Divorced.	Y	Y	H
P14	50	3	N	N	Lived alone.	Y	N	U
P15	37	3	Y	Y	Lived with husband and 2 children	Y	Y	H
P16	50	0.5	Y	N	Lived alone. Divorced.	Y	Y	H
P17	45	2-3	N	Y	Lived alone. Divorced	Y	Y	H
P18	52	1	N	2	Lived with husband.	Y	N	H
P19	25	1	Y	N	Lived alone	Y	N	U

P20	57	1	N	Y	Lived alone	Y	N	H
P21	52	0.5	Y	Y	Lived with husband.	Y	Y	H
P22	55	2	N	Y	Lived with teenage daughter	N	N	H
P23	37	2	Y	Y	Lived with daughter	N	N	H

**Table 7 Demographic, FMS and interview related information of study participants**

was complex and consisted of unique, overlapping and at times polarising issues. Findings from this study will be presented to suggest that the participants all started with a restitution narrative when they initially became ill but this was left when the expected outcome failed to become enacted i.e. they didn't get better. None the less throughout the study the majority of participants continued to emphasise their desire to return to this narrative and lived in hope of a 'cure' being eventually found.

Within their stories it was possible to identify the difficulties they encountered in being diagnosed and it was during this period that the chaos narrative was dominant. For all of the participants there was then a process of transition as the problems posed by becoming individuals living with FMS were recognised by society and then acknowledged or rejected by themselves. Following this many of the participants described a narrative characteristic of quest and told of a return to a life story that was never the same again.

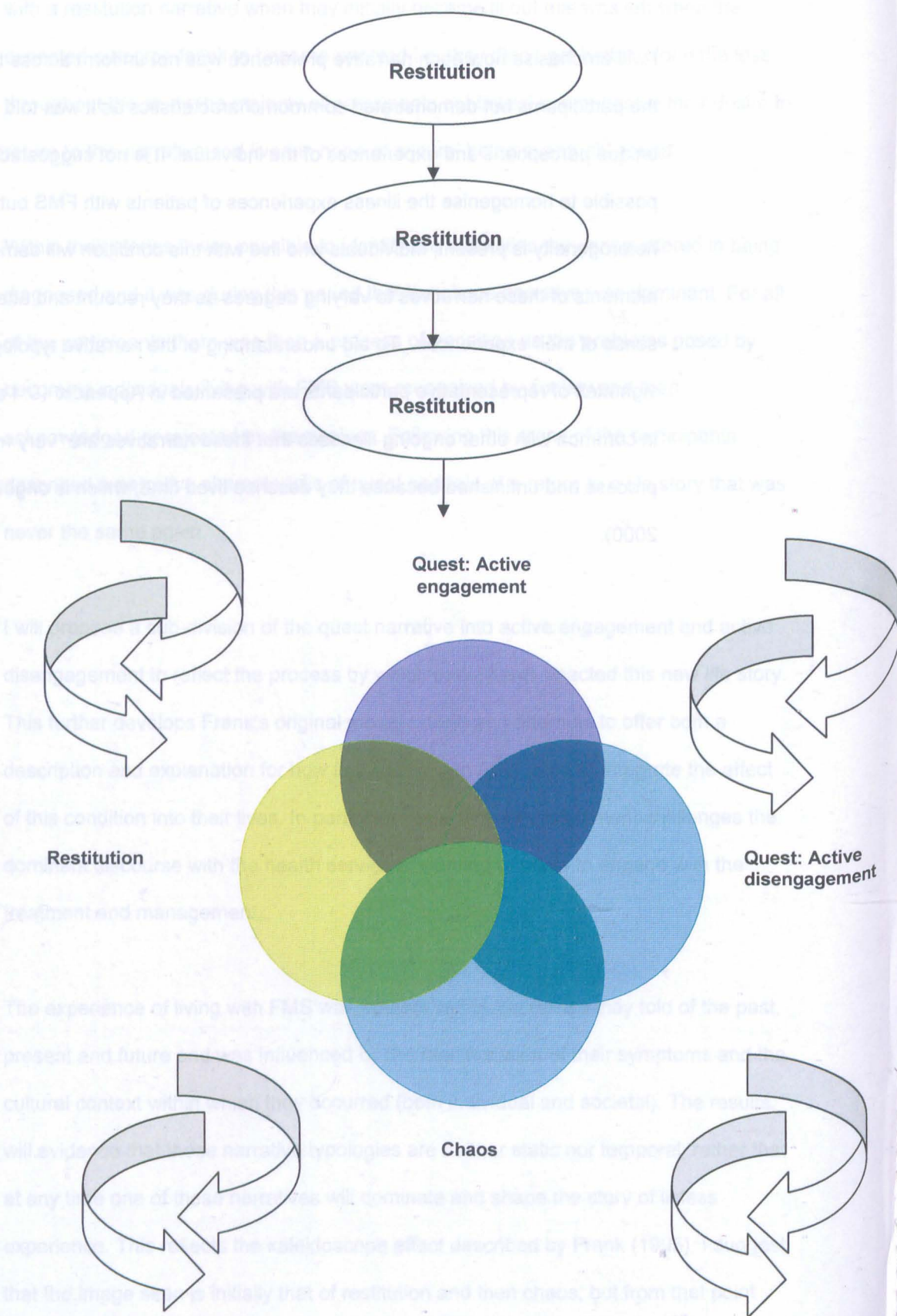
I will propose a sub-division of the quest narrative into active engagement and active disengagement to reflect the process by which participants enacted this new life story. This further develops Frank's original model (1995) and attempts to offer both a description and explanation for how individuals with FMS learn to integrate the effect of this condition into their lives. In particular the active disengagement challenges the dominant discourse with the health service of wanting patients to engage with the treatment and management.

The experience of living with FMS was present within the stories they told of the past, present and future and was influenced by the manifestation of their symptoms and the cultural context within which they occurred (both individual and societal). The results will evidence that these narrative typologies are neither static nor temporal; rather that at any time one of these narratives will dominate and shape the story of illness experience. This reflects the kaleidoscope effect described by Frank (1995). I suggest that the image seen is initially that of restitution and then chaos, but from that point

whilst often taking one dominant form, it can rapidly shift, with a changing image then being visible. This is shown in figure 3.

I will emphasise how each narrative preference was not uniform across the stories of the participants but demonstrated common characteristics as it was told through the unique perceptions and experiences of the individual. It is not suggested that it is possible to homogenise the illness experiences of patients with FMS but that heterogeneity is present; individuals who live with this condition will demonstrate elements of these narratives to varying degrees as they recount and attempt to make sense of their experiences. To aid understanding of the narrative typologies truncated vignettes of representative participants are presented in Appendix 10. I advocate that, in common with other ongoing illnesses that these narratives are "very much in-process and unfinished because they describe lived time, which is ongoing" (Ezzy, 2000).

**Figure 3. The kaleidoscope of 'quest, chaos and restitution narratives' in individuals with FMS**



## **5.4 Restitution narrative**

The restitution narrative (as discussed in section 4.5.4) is most commonly evident in stories of acute illness. It is characterised by the story line "Yesterday I was healthy, today I am sick, tomorrow I will be better again" (Frank, 1995, p.77). This narrative appeared to be evident at some point in the stories of all the participants. At the initial interview the restitution narrative was dominant as the participants described the lives that they had lived prior to and at the initial onset of symptoms. Their stories then became dominated by the struggle to be diagnosed and became consistent with a chaos narrative. With diagnosis chaos was suspended and restitution became dominant as hope of a cure or effective management returned. As time passed either chaos returned or quest emerged in the foreground as they experienced the effects of living with FMS. However, the presence of restitution in their stories never completely disappeared and participants periodically verbalized how they hoped one day to be enacting this preferred story.

The presence and reappearance of the restitution narrative did not always occur in a linear fashion or at consistent time frames within the stories of the participants. As well as the relationship to health, the restitution narrative also appeared to be related to their ability to rely on their bodies and for it to respond in a 'normal' way and for their lives to be perceived as predictable and ordinary. The results of this study thus suggest further elaboration of the story line to encompass two further dimensions: 'yesterday my body was reliable and responsive, today it isn't, but tomorrow it will be once more' and 'yesterday my life was ordinary and predictable, today it isn't but tomorrow it will be once more'. Evidence to support this will be presented throughout the description of how the restitution was enacted in this study.

### **5.4.1 An ordinary life**

The theme of an ordinary life characterised the descriptions that participants gave when asked to describe the period of their lives before the onset of FMS and was most dominant in the first interview. It was also a theme that was revisited throughout



the course of the study as they compared and contrasted their life with FMS to that which had previously been experienced and the future they had hoped for. It appeared that they had considered their bodies, their lives and themselves no different to anyone else and inherent within these dimensions of being was a notion of predictability. Whilst they could not deny that unexpected events did take place, for the most part planning and organisation was visible and effective.

#### **5.4.1.1 A reliable and responsive body**

The sub-theme 'a reliable and responsive body' dominated the period of time before the onset of the symptoms of FMS. This sub-theme and period of their life reflected the "yesterday I was well" element of the restitution narrative. It was characterised by the sense that whilst they were aware that they had a body it did not normally need to be considered when planning and living their lives. It appeared as though their body was taken for granted with tacit knowledge of what it could be expected to do and how it could be expected to react. Malfunctioning of the body i.e. the occurrence of illness or disease was to be expected and 'normal', as was recovery when remedies and actions were put in place.

Prior to the onset of symptoms the majority of participants (n=17) were employed in some capacity, although this had reduced to n=8 when they were recruited in to the study. Being able to go to work was considered part of living a 'normal life'. Not working was something that had been chosen e.g. so they could adopt the role of carer or mother, or the result of being unable to find a job. The routine and physical demands of employment had been managed within the context of their every-day lives, and it was the exception rather than the norm for them to have to consider their bodies' ability to fulfil these demands. Their body could be depended on to allow them to go to work and in doing so they were often able to achieve their ambitions and feel a sense of accomplishment. This is typified by participant 16, in her first interview, who had been working in a nursing assistant role:

"I never had to think about whether I could get up and do my job. Yes, sometimes I might be tired or under the weather but that's normal. You could normally carry on or if not a few days rest and some paracetamol and you'd be feeling a lot better. I had a good job working in the NHS and felt that I'd achieved something. You know, I was doing something I enjoyed and helping other people"

Over 50% of the participants (n=13) had been married or in a long term relationship at the onset of symptoms, and n=7 had children who were still living at home. Routines, relationships and roles were described together with discussion of how each member of the family was usually supported to ensure that life ran as smoothly as possible. In doing so each individual was able to fulfil their obligations, and re-negotiation of roles and routines would take place to meet the needs of the family and individuals. It was rare for their bodies to have to be considered other than in the context of whether they had the physical attributes to do something. For example, participant 5 in her second interview described how she and her husband would both get involved with DIY tasks about the house, before she was ill, but he would perform a lot of the heavy manual work "just because he was stronger".

Providing they had the ability to perform a task or a role they would usually not have to consider whether their bodies had the capacity to perform it. This wasn't confined to physical tasks and would encompass mental tasks as well e.g. helping children with their homework, managing home finances. In particular they frequently highlighted how good their memory and concentration had been prior to the onset of FMS and these were both attributes that they grieved for when they became ill. Emphasis was placed on how they could rely on their body to respond and perform when they wanted to. This is demonstrated by participant 14 who had been attending college prior to her illness and had hoped to return to study but felt unable to as she could no longer rely on her memory:

"And I was hoping to return to work eventually. I'd enjoyed college before, really felt like I was beginning to get my life back on track. But now I can't see that happening. Before, I had to work hard, and my memory wasn't like when I was young. But I could do my work, remember what I'd learnt and especially where I needed to be everyday. Not now. Sometimes I forget where I'm supposed to be and I seem to go over and over the same thing and my brain just doesn't seem to work like it should any more".

Similarly they described how they used to take for granted their bodies in the planning and performance of everyday activities. Planning was used to ensure that everything took place as required rather than to compensate for the needs of a body that was unreliable and ineffective. Their lives were frequently busy with competing demands of home, work and social pressures. The pace of life was not considered unusual and there appeared to be little overt consideration of how their bodies would respond and subsequently feel. This was typified by participant 9 who worked full-time for the council and had 3 children. In her first interview she reflected back on what she had then considered to be a 'normal' routine prior to the onset of FMS:

"I look back now and realise how I took it for granted. I went to work, came home and looked after the children. I didn't think about whether I would be able to do it today, tomorrow or the next day. I just did it, it happened"

Participation in social activities appeared to be embedded in their lives and a consequence of what they wanted or had to do, as opposed to what their bodies were physically able to do. They all described socialising with family and friends in ways that were both spontaneous and planned. It was inevitable that changes to plans were sometimes made. However, these were acceptable and rarely due to the needs of one person alone. There was no differentiation apparent between them and their peers; living a sociable life was normal and something they relied on their bodies to be able to do.

The reliance and responsiveness of their bodies was also evidenced in the physical relationships many of them described with their partners prior to the onset of FMS. Other than the two participants who were carers, those participants who had been in relationships prior to the onset of FMS described how they had enjoyed what they considered to be 'normal' sexual relationships with their partners. They acknowledged how it was normal for one of them to sometimes decline taking part in sexual activity but this was not on a regular basis and was usually due to a global feeling of 'not being in the mood'. If they wanted to participate they did not give much consideration to whether their bodies would be able to 'cope with it' i.e. they didn't have to think about whether it would hurt at the time or afterwards. This is described by participant 10 in her second interview when she was recalling the physical and sexual relationship with her husband:

"I'm lucky in one respect because he is an emotional person and sensitive. He's not highly sexed, never has and never will be, but we all have those needs. Before it wasn't an issue, but now at night I'm exhausted and we have to make time when we're both relaxed. Before we didn't have to think about it, plan. He'd just give me a cuddle but sometimes I think he's frightened to cuddle me now"

Intimacy had been a pleasant experience which they had both enjoyed and they emphasised how, before FMS, their partners weren't wary of hurting them with physical contact.

At home, work and play there was an acknowledgement of the presence of the body as a physical entity; bodily sensations of pain and fatigue were described as normal sensations and an inevitability of life. It was expected that when they had been busy or as they grew older to feel tired. They recalled how they associated sleep and going to bed as something that would restore feelings of well-being. They often felt tired: it was a usual sensation that would be reduced or abolished by either 'taking things easy' or 'getting a good nights sleep'. Similarly if they exercised, were busy in the house or

sustained an injury it was normal to experience pain. Aches and pains also became expected as they were 'getting older'. Like tiredness, there was nothing abnormal in the sensation and it would usually resolve given time or the use of some sort of remedy e.g. painkillers, heat, ice.

As they reflected on this time of their lives there appeared to be two contrasting threads to their stories: they were able to describe how they had been able to depend upon themselves and their bodies to meet the normal obligations of life and embrace opportunities and challenges as they arose. However, they also acknowledged how tired they had sometimes been and how hard they had 'tested the limits' of their bodies. Later on they would question whether this had been a contributing factor to the onset of their illness. This is demonstrated by participant 8 who described how busy she had been working full-time as a publican, whilst at the same time supporting her family of 2 children who were now grown up:

"I look back now and I think about how busy I was, physically moving things about and working all hours. And I tried to be there for the family too but it was hard when you're so tired. And you do wonder- did I overdo it? Did I wear myself out?"

The over-riding theme appeared to be that although their bodies had not always felt or acted as they'd have liked, their bodies did act as they would have expected given their individual circumstances.

#### **5.4.1.2 Every day is normal**

Contained within the theme of an ordinary life was the sub-theme of 'every day is normal'. Within the context of their first interview all participants either spoke or were asked about, what life was like before they had FMS. Their replies were characterised by the notion of 'being the same as everybody else' and every day was 'normal'.

However, reading of the transcripts by my supervisor (Mark Avis) and I led us to draw the conclusion that their lives were often in my words "anything but ordinary". Most of

the stories were characterised by the presence of major life events in the years preceding the onset of FMS. These included sexual abuse (as either an adult or child), bereavements (of children and partners), and drug abuse within the family. These events that to us seemed 'out of the ordinary' had seemingly been interpreted as 'normal' events and absorbed into their lives. Whilst for example sadness, anger, grief and distress appeared to be evident when they described these events, they nonetheless appeared to have been processed and considered part of the normal passage of time.

The "yesterday I was well" element of the restitution plot line was evidenced in the way that when they were well they could plan their lives and generally those plans would be fulfilled. This was further evidence of the proposed theme 'yesterday my life was ordinary'. Life was composed of 'normal' facets and obligations: work, home and social. Being well enabled them to fulfil these and even when they were ill, there was an expectation that given the use of an appropriate remedy 'tomorrow they would be better' (Frank, 1995) and life would resume as previously to being 'ordinary' once more. Tacit knowledge and experience had given them the ability to judge when this would be and thus whilst illness might temporarily interrupt their lives, 'normality' and usual routines would soon be resumed.

The majority of participants (n=17) had been employed prior to the onset of FMS. They defined their jobs, the routine of employment and how this was managed within their everyday lives as consistent with what they believed constituted 'a normal day'. The absence of contingency enabled them to manage work alongside other demands they had and this is typified by participant 2 in her first interview. Prior to FMS she had been working full-time as a care worker in the NHS, taking her youngest son to nursery when she wasn't in work:

"Whatever happened I used to go out to work every day, I used to go to work every day no matter what".

She had another son who had attempted suicide and yet she had still managed to go to work and fulfil what she saw as her obligations, and part of what constituted a normal routine.

Prior to the onset of FMS many (n=13) of the participants were married or in long-term relationships and n=7 had children still living at home. Every day was considered normal and involved the management of domestic routines and relationships. This required all of them to have negotiated roles and responsibilities e.g. parent, provider, carer. The predictable pattern of life at this time appeared to allow each member of the family to fulfil these duties and life ran as smoothly as was possible. These roles were not static and sometimes changed but within the context of what they considered normal every day life. This often involved planning to accommodate all of their needs and was rarely due to being ill and not responding to treatment in a timely manner. It was also uncommon for changes in life to have to be made consistently on account of one person. This is evidenced by participant 11 who had 2 children and was married, and her husband worked full-time. She worked part-time but also did some voluntary charity work overseas:

"I mean, we all worked together to make sure things happened. Sometimes we had to be quiet because *the husband* was working extra shifts, but that wasn't for long. And when I used to go abroad to do work on setting up a school they would have to manage at home on their own. But everyone had their turn and we supported each other. There was no one person who had to be considered all of the time"

The participants told of how prior to the onset of FMS they took for granted the activities that they performed in their normal everyday lives. Planning was evident but this appeared to be to ensure that the normal routines and activities of every day life took place rather than to compensate for how they were feeling. Their lives were frequently busy but this pace of life was not considered unusual and rarely did they

have to consider the impact of this on how they might feel subsequently. For many, every day appeared to be the same and no special consideration was given to whether or not they would be able to participate in what was needed. Consistent with the restitution plotline of 'tomorrow I will be better once more' (Frank, 1995) when illness happened there was an expectation they would get better and life would continue as normal, predictable and ordinary demonstrating the parallel plot line of 'tomorrow life will be ordinary once more'. Participant 9, a mother of 3 children and working full-time highlighted this as she reflected on her normal routine prior to the onset of FMS:

"I look back now and realise how I took it for granted. I went to work, came home and looked after the children. I didn't think about whether I would be able to do it today, tomorrow or the next day. I just did it, it happened"

Social activities and routines appeared to be embedded in their lives and a consequence of what they wanted to do or had to do, as opposed to what they were physically or mentally able to do. All of the participants had friends and family that they would socialise with and to do so was considered part of what constituted living an ordinary life and being a normal day. Social activities were both spontaneous and planned and it was both acceptable and inevitable that sometimes changes had to be made. They recalled how before they were ill they had been no different to their peers. Participant 5 told of how they used to as a family go on camping trips, but sometimes due to her husband's work commitments or if one of the family was ill, a trip would have to be cancelled. However this was "just normal" and was no more frequent in their family than in any other:

"and we used to go away camping a lot, the family. We'd just go at the drop of a hat. But sometimes if he (*the husband*) had to work over-time or one of us were ill we'd cancel. It didn't happen often and was well, just normal"



Embedded in the stories they told of life prior to FMS were descriptions of the relationships that they had with their partners (be they seeing someone, living together or married). These relationships helped define what was typical of 'normal everyday life'. This encompassed recollections of how they used to engage together in social activities ranging from going out to a pub or restaurant to walks and trips away. Whilst they had to consider their other commitments e.g. work and family life, they never had to consider their bodies when they participated in these things. These activities could be planned or spontaneous and this reflected what they considered to be a normal life.

They also emphasised how at this point in their lives the normality of each day was present in the intimacy and physical relationships they had with each other. On a normal day intimacy between them might be evidenced in the participation in sexual activity with each other or the spontaneous physical contact of a non-sexual nature that they used to enjoy e.g. kisses and cuddles. They weren't fearful of how their bodies might respond when touched and thus they would regularly kiss, touch or simply hold each other demonstrating their feelings for each other. There were also descriptions of small gestures that demonstrated consideration for the other person e.g. taking a cup of tea to bed in the morning. At this time both of them equally participated in these gestures.

#### **5.4.1.3 A rational explanation**

The sub-theme a 'rational explanation' was developed from the responses that participants and their partners gave when asked to describe the initial onset and their response to the symptoms. All of the participants demonstrated the restitution narrative when they recalled their previous recognition and management of illness, and the onset of the initial symptoms of FMS. The components of "today I am sick, tomorrow I will be better" (Frank, 1995 p.77) were evidenced as they recalled this period of their lives. Consistent with FMS literature (Wolfe et al, 1990; Adams and Simm, 1998; Richards and Cleare, 2000) the symptoms of fibromyalgia had begun insidiously with the gradual onset of pain and fatigue over a prolonged period of time.

For participant 1 this had been over 6 years in contrast to participant 5 who had only had symptoms for 6 months. Initially none of the participants appeared to interpret these symptoms as anything out of the ordinary and there had been no indication that they would last any longer than a week or two. A key theme at this stage was that there was a 'rational explanation' for everything that they were experiencing.

The symptoms initially were 'normal bodily sensations' and recognisable from past experience. They told of how at this time they had explained their presence using prior knowledge of health and illness. Tiredness and pain were attributed to a number of predisposing factors including: activities that they had participated in, their age and the expected onset of arthritis, a recent illness, the consequence of a hectic lifestyle or a recent stressful life event. They didn't dwell on how they were feeling and anticipated that these symptoms would either resolve or that they were inevitable. Participant 4 had previously been treated for tennis elbow. Knowing how this had resolved with time and a steroid injection she did not think the onset of pain in both of her arms was particularly unusual and had continued to explain her symptoms and anticipate they would eventually improve:

"And it started about a year ago. Stiffness and pain on getting my arms in to garments. And I thought I must have had a bad night or something"

Pain was the most common symptom described by participants and in keeping with the typical presentation of FMS (Wolfe et al, 1990; Adams and Simm, 1998) pain was widespread and felt in no consistent area of the body. Some described the onset of pain felt in all areas of their body whilst others described how the pain had begun in one area and then subsequently spread to other joints and soft tissues. Recalling their pain the participants used terminology such as 'aching' and 'stiffness' appearing to imply that the pain at this point was benign and non-threatening. At this point it didn't seem to be anything out of the ordinary. Participant 8 working at this time as a publican performed a heavy and predominantly manual job. She described the pain

she felt, how she tried to identify a rational explanation for it (she thought she had injured her shoulder) and how she had tried to alleviate it with self management:

..it's crunching (*my shoulder*) 'cos I thought something was trapped so I used to move it, to try and loosen anything up if it was there"

Sometimes the pain was exactly the same as symptoms that had been experienced before. The familiarity of symptoms led to attempts to try and manage them using their normal armoury of pain relieving strategies including over the counter analgesia, thermal modalities, exercise and rest. This once more was consistent with the restitution plotline and the modernist perspective that for every illness there is a remedy. They thought of these as short-term management strategies that would be used until the symptoms had diminished or resolved. Participant 16 who worked as a nurse within the NHS described how she had initially associated the onset of her symptoms with perhaps having injured herself at work:

"When it first began I just thought that I'd strained my back. It ached and I'd had pain in my back before and taken painkillers which helped. I thought that if I just took them for a few days then the pain would go away" Participant 16

Tiredness was the other symptom most commonly described in the early stages. As with pain the fatigue they were experiencing was recognisable, part of living a normal life and not considered unusual. Participants told of how at the time they attempted to provide explanations for why they were feeling as they were. Typically these were related to common illnesses such as the flu or a virus, the product of a hectic lifestyle or simply getting old. Participant 14 characterised this with the recognition that at this point the fatigue was considered transient and there was an expectation that life would eventually return to normal:

"I mean I'd had times before, when I'd been under the weather, had a virus or something, even had time off. Things would always get back to normal. This was no different"

At this point these sensations were felt in a way that was familiar and still enabled them to participate in their lives with minimal interruption or adaptation. Tiredness was not always a negative attribute but at times a positive external manifestation of the days' accomplishments. In addition the participants evidenced how they were acquainted with considering the cause of the problem, and finding a solution to bring about their resolution e.g. taking a painkiller for any bodily pain or resting if excessively tired. This was consistent with the restitution plot that for every illness there is a remedy (Frank, 1995) and the notion that tomorrow their body would be reliable and responsive once more.

The participants told how being ill was also normal and all of them gave examples of other occasions when they had been ill. These included both minor and more serious illnesses and operations. Once more they described themselves as being ill rather than their body. In distinguishing these illnesses from fibromyalgia they highlighted that there was usually a rational explanation for how they were feeling and that given the appropriate treatment, symptoms were managed or alleviated. In describing her previous experience of having ovarian cancer participant 10 recalls:

"And I had ovarian cancer. I had chemotherapy, radiotherapy, the whole 'shebang'. But that was 16 years ago and I've been okay since"

Often when describing symptoms of pain, fatigue, tiredness or illness they did not separate the body and self; they were tired not their body. The body and self were integrated and the body not usually acknowledged at a conscious level. On occasions the problems posed by their body not functioning as 'normal' became more evident and it impacted on their life experiences and perceptions. They were used to seeking

solutions to these problems and usually they could be resolved alone or with the use of medication or medical intervention. Reflection on previous experience of illness in finding remedies was common and if all else failed usually time proved to be the 'healer'.

When the participants initially began to feel unwell they all expected to get better irrespective of which symptoms presided or how they began. There was nothing untoward in the symptoms or their onset. All of the participants anticipated getting better and there was nothing unusual in their initial symptom presentation that made them consider that this usual return to 'good health' would not occur. They attempted to provide rational explanations for their symptoms and this was repeated in their encounters with health care professionals, their family and friends.

The participants were asked at what point the symptoms were considered 'out of the ordinary'. Consistently this was associated with 'not responding as anticipated' and no longer being able to provide a 'rational explanation'. In this respect the restitution narrative for most participants was still evident. Over time symptoms failed to respond as expected and often even worsened; the participants described how further help and advice were then sought and the time threshold for this appeared to be influenced by tacit expectations of what 'normally would have happened'. These expectations were not just theirs but reinforced by the beliefs of their friends and family who also encouraged them to seek help. For all the participants the next step in 'normal illness management' was to seek a medical opinion and this was from the GP. This is demonstrated by participant 6, a butcher, who described how his wife insisted he went to his GP when the symptoms of aching in his legs failed to improve:

"Well I'd tried rest and I'd tried tablets but nothing seemed to be making a difference. But it was her (*his wife*), she made me go to the doctors. She said you can't go on like this, something must be wrong. But I didn't want to be complaining"

This part of the narrative became dominated by medical consultations and an adherence to the biomedical model of health. The health care professionals themselves appeared to be 'enacting' the restitution narrative and attempting to find an explanation for their complaints. Symptoms were explained to their GP who was unable to find any physical abnormality. It appeared that rational and predominantly biomedical explanations were given and this further reinforced beliefs that it was 'a virus', 'age' or simply 'over doing it' and things should improve given time. As the symptoms persisted there were further visits to the medical practitioner to ascertain why they had failed to improve.

Physical tests were done and in the absence of any significant findings diagnostic tests were performed. These were commonly radiological investigations and blood tests and with each test that was performed the participants had high expectations that something would be found to explain their symptoms. Many resources often appeared to be expended in the search of 'abnormality' with the belief that once found restitution would be enacted with the provision of an appropriate remedy.

It also appeared to the participants that for restitution to be enacted and illness to be validated the medical practitioner seemed to be placing greater moral and scientific weight on the results of objective tests rather than the subjective symptoms they described. When tests were normal they reassured participants that there was nothing untoward in their symptoms and that they should resolve over time, with the use of prescribed medication or with physiotherapy. This is highlighted by participant 19, a nursing assistant, who talked about her experience of low back pain which she initially attributed to her work. After 2 months she sought help from her GP:

"I started with really bad pains in my back and I carried on until June/July. They (*the GP*) told me it's your back and to go for physiotherapy. I thought it would get better. After having physiotherapy my back did get better but everything else was painful and horrible"

Similarly participants described how when tests did occasionally identify abnormalities e.g. arthritis, symptoms were readily attributed to these credible findings and the corresponding medical treatment given. In hindsight some of the participants were able to identify how these explanations didn't always adequately explain the symptoms. This is discussed by participant 1 who had sought help from her GP after experiencing pain in her back and legs for approximately 6 years but not sought help until the onset of inexplicable tiredness. She had x-rays which identified some arthritis in her lumbar spine and her symptoms were attributed to this:

"...it just came on gradually. I was having problems with my back and hips. I went to my GP who sent me for x-rays and blood tests and that. And they found some arthritis in my spine. Nothing much. It wasn't a lot but they just put it down to 'oh it's the arthritis'"

She now thought that whilst this would have explained her pain symptoms it did not explain the tiredness.

At the time of symptom onset, and when in the short-term there was a lack of improvement, many of the participants withdrew from their roles at home or at work. This was anticipated to be a short term measure by themselves, their family, work and often their GP. Rest as a strategy to facilitate the return to health was considered normal illness behaviour and frequently encouraged. Once more this enacted the restitution narrative belief that 'today I am sick and tomorrow I will be better' (Frank, 1995) with rest seen as an appropriate and rational management strategy for the symptoms they were experiencing. This was different to 'laziness' and in the initial period of illness at times a failure to rest was seen as deviant behaviour.

It was expected that combined with other normal illness behaviours such as the taking of medication, this relinquishing of responsibility and duties would be short term; once

symptoms had resolved they would be able to recommence their normal roles and life for all would continue as previously. In the absence of a definitive medical diagnosis this exemption from normal duties was less readily extended by the participants immediate support network. The absence of a diagnosis continued to fail to provide a rational explanation for their actions. For example participant 5 highlighted the difficulty her husband had in taking time off work to help her when it was not clear what the specific nature of her problem was:

“What he struggled with was people at work, Before I was diagnosed, because it’s such a non-specific illness, it’s not like I’ve got cancer or a broken leg erm, he’d, he’d go to work and his work colleagues would say “oh what’s the matter with her?”, “we don’t know”, “oh”. It was almost like they didn’t believe him. But there’s times when he’s had to have time off work to look after me. Because I wasn’t diagnosed, the work place aren’t that supportive of like being off with your wife, but they don’t know what’s wrong”

For both the participants and the medical practitioner it was the beginning of a process of both elimination and reassurance. Positive results were used to provide credible explanations and negative results to affirm that nothing was wrong. In the short-term the medical encounter provided the patients with a credible explanation for both how they were feeling and potential treatment. The biomedical model was dominant and aligned with the restitution plot line. It appeared to be familiar to the participants and continued to be utilised by both them and their medical practitioners even when the symptoms failed to resolve.

#### **5.4.1.4 In search of a diagnosis**

The sub-theme ‘in search of a diagnosis’ was strongly linked to the restitution narrative; without a diagnosis, remedy and resolution were not possible and they were unable to enact the component of ‘and tomorrow I will be better’ (Frank, 1995). This was also linked to issues of ‘noticing something was wrong’ and concerns about ‘is it



something serious?' It formed part of the theme 'an ordinary life' as this was what they would normally expect to take place given the presence of ongoing medically unexplained symptoms. If you weren't getting better it was normal to find out what was wrong.

For the majority of participants (n= 20) it was some years (range from 0-5 years) before they considered whether 'something was wrong' and sought help. For 3 of the participants (1, 16 and 21), help was sought within a short period of time (<1year). It was not possible to discern from the interviews any difference in symptom severity between these and the remaining participants. The threshold to seek help by all participants was influenced by their own individual beliefs and perceptions about the symptoms they were experiencing and the impact on their lives.

For the majority it was the cumulative effect of the pain and fatigue that concerned them, whilst for others it was the lack of adherence to the usual model of onset, treatment and resolution. They were influenced by their inability to live their 'normal' lives and began to lose confidence in their own explanations for their symptoms as well as those provided by their GP. Participant 8 was used to feeling tired in her job as a publican and to experiencing joint and muscular aches and pains owing to the physical nature of her job. However she recalled how when these symptoms continued to return with increasing severity the rational explanations she'd been used to giving no longer felt adequate:

"And some days I didn't feel it at all and other days I did. And as the years went on or the months went on and it was worse and worse and worse so I kept on going back to the doctor 'cos I weren't happy with what he was saying"

When participants failed to respond to the strategies proposed by their medical practitioners and tests were returned as 'normal' the chaos narrative began to become evident. This was reinforced by the continued lack of diagnosis. Most of the

participants were beginning to get increasingly concerned about the absence of any biomedical markers coupled with the increase in, and persistence of, their symptoms. They continued to want to enact the restitution narrative but were unable to do so and searched for alternative explanations that would enable them to retain this plot line. Even though alternative explanations for their symptoms might have been unpleasant they were explanations that they were familiar with.

The invisible nature of their symptoms made them question whether there was something "seriously wrong" that had been overlooked. They could all recount stories of people they had known or had heard about who had described such symptoms and turned out to have other serious illnesses, cancer being their main concern. Participant 11, had previously worked as a registered nurse and had initially complained of generalised aches and pains but then these had localised to her shoulder, hip and knee. She had been to her GP and was not satisfied with the biomedical reason for her symptoms that had been given. Having some medical knowledge she had begun to question whether pathology was being missed:

"..I thought there's definitely something wrong. I wouldn't be getting all these horrible aches and pains, all over me body. I thought I'd got cancer at one stage, you know of the bones or something"

Participants also identified how the cumulative effect of their symptoms led them to stop engaging in activities that they had previously enjoyed and considered part of their every day lives. Whilst for some of them this was simple jobs around the house such as decorating (Participants 3, 6, 8, 11, 21 and 23), for others it was a withdrawal from social activities such as exercising (Participants 2, 4, 17,18) and for all socialising both within and outside the home with friends and their family:

"Several years ago I had an accident with my left wrist. It wasn't exactly broken but I don't know exactly what I did and this was working in the factory. I noticed it was

getting painful....but the like I say the base of my back went and then I started finding everything was stiff and sore and you know I was having trouble doing all kinds of things that I'd always done and enjoyed doing all me life. Decorating I found I couldn't hold the brush. Just silly things that I'd always took for granted that I found extremely hard to do" Participant 3

They were continuing to use their past experience of illness as a model for the symptoms they were now experiencing. As, in the case of participant 3, it was often the mundane nature of things that they couldn't do, as well as those that they enjoyed, that triggered a concern that all was not as it should be. It was considered part of normal illness behaviour to seek out an explanation when usual remedies and self management had failed to bring about resolution.

It was at this stage, as they searched for a possible diagnosis, that a small number of the participants began to question whether their symptoms were psychological in nature. A small number of them were being treated for depression (3, 9, 20, 22) prior to the onset of their symptoms and wondered whether this was another manifestation of their psychological well being. This was most commonly considered as an explanation for their tiredness and loss of concentration, but some of them also wondered whether it would explain why their symptoms were so variable both in intensity and site. They contemplated whether this explained why the symptoms and their lack of response were also at odds with their previous knowledge of how illnesses that were biological in nature normally manifested themselves.

Participant 9 had been recently bereaved and off work as a result of this. She had previously had problems with low back and neck pain. On return to work she complained of pain in her upper limbs but then noticed them in her low back and legs; shortly after she also suffered with headaches and tiredness. She consulted her GP who initially diagnosed her with arthritis but when her symptoms did not resolve she

felt this was an inadequate explanation but wondered whether it was due to her mental health:

"I thought it was just depression...it's probably the running around with him (*her husband when he was ill*), the running around with the children, the everyday chores that you do get tired and then maybe its' stress and depression"

The potential at this stage to attribute their symptoms to a psychological cause appeared at this stage to be an attempt to resolve the issue of diagnosis themselves. As such it appeared to be lacking in stigma and the possibility of psychological causes being responsible for their symptoms still appeared to allow them to remain within the biomedical model. These weren't symptoms that were being 'made up' but instead they were prepared to consider whether they were the physical manifestation of some psychological disorder such as stress or depression. Whatever the potential explanation for their symptoms they were no longer satisfied with the interpretations offered that had been offered and were prepared to consider all reasonable accounts. This would allow them to remain within the restitution narrative as it offered the potential to consider alternative management strategies that would ultimately lead to symptom resolution.

When participants failed to respond to strategies proposed by their medical practitioners and tests were returned as normal the chaos narrative began to become evident. This was reinforced by the continued lack of a diagnosis. To remain in the restitution narrative and ultimately fulfil the expectations of society it appeared that participants required a definitive diagnosis. In its absence there appeared to be the perception that society generally considered that they were failing to meet its unwritten expectations.

Descriptions of symptoms such as "achey legs" (P6), tiredness and multiple joint pains seemed inadequate especially when justifying to external agencies e.g. employers,

their continued inability to fulfil responsibilities. Sometimes this led to them questioning their own illness legitimacy but for the most part they felt that medical care was failing them in not providing them with a diagnostic label and ultimately treatment and cure. This is demonstrated by participant 12 who had previous experience of being diagnosed with a "leaky heart valve". When the symptoms of FMS had begun she had been investigated for angina. When tests for this were negative she was discharged with no further follow-up by the hospital. From her past experience she felt that further investigations were necessary to find the cause and then treatment/condition management could be instigated. For this reason she requested a referral to a Rheumatologist as her friend had found it helpful when she had problems with her joints:

"And my friend she said she'd seen a Rheumatologist when her legs were hurting her, and they'd found out she'd got arthritis. And I still wasn't getting anywhere, so I went to see him and asked" Participant 12

"When you went to see your GP did you have a battle for that referral or as soon as you went to see them they said "we'll send you"" CJD

"No, no. I just says to him "I want to see a Rheumatologist because I want to know what is wrong. Couldn't see how I could get better if I didn't know what's going on" Participant 12

The restitution narrative did not reappear for any of the participants as the dominant storyline until they were referred to Secondary care for an expert opinion. Until this time chaos reigned.

#### **5.4.2 Knowing what's wrong**

The acquisition of a diagnostic label had a significant role to play in the presentation of a restitution narrative. In the early part of the study it appeared to be symbolic of hope:

hope of being a credible patient, hope of treatment and ultimately cure. Over time however the meaning attached to the diagnosis was mediated as none of the participants were cured and there was failure to enact the end point of the restitution narrative i.e. 'tomorrow I will be better' (Frank, 1995). There was also by association an inability for their bodies once more to become reliable and responsive or for their lives to return to being ordinary.

Being diagnosed with FMS had brought with it the knowledge of what was responsible for their symptoms but it had failed to enact the modernist perspective that for every illness there is a remedy (Frank, 1995). They now seemed to have to face the reality of living with a chronic condition where the future, be that tomorrow or long term was uncertain and the restitution narrative was left once more to remain in the background. The participants then either returned to stories where chaos or quest became the dominant plot lines.

#### **5.4.2.1 The significance of diagnosis**

For the purpose of this study sampling was from a Secondary care setting where participants received their diagnosis from a Rheumatology Consultant or medical member of their team. The emergence of a restitution narrative became evident for most participants as they recalled their experiences of being told they were to be referred to a Consultant, 'a specialist' someone who could provide the answer to why they were suffering and then cure them. In contrast a few of the participants had already been seen by Consultants in other specialities and recalled a negative experience. The dominance of the restitution narrative for them was suspended until their actual consultation doubtful of what this 'other' specialist could offer.

At the consultation with the Rheumatologist further tests were performed and for the majority of the participants it was the first time they felt they were listened to. Weight was given to the symptoms they described and this was used as a basis to examine them, find the tender points of FMS and ask the 'right' questions. This gave them

confidence and hope that finally a 'truth' would be discovered about what was wrong with them.

A minority (1, 5, 16) were aware that the diagnosis of FMS was being considered when they were referred on whilst most had still not 'heard' of FMS. One participant had already considered that she might have this diagnosis following research she had conducted on the internet. She thought that confirmation of this by a medical practitioner would be a positive experience but the reality was different:

"I think maybe in my head, I had it in my head that, once I knew I'd feel ten times better, but I didn't feel any different. Which is odd" Participant 5

However, the same participant was representative of the sample in feeling she was now 'on the road' to getting better. Like all of the participants her life had been adversely affected by the symptoms of FMS and not knowing what was causing them. By the time she had been diagnosed she had had to give up work, was unable to participate in family activities e.g. going camping or for walks, or contribute to household tasks in the same way. The receipt of a diagnosis had brought with it the opportunity to tackle the condition, the symptoms she was experiencing and the situation she had now found herself in:

"I was glad I was diagnosed because that's half the battle" Participant 5

Being diagnosed symbolised the start of being able to access information, treatment and benefits. All of the participants were given the ARC Fibromyalgia leaflet (ARC, 1999) by the Rheumatologist which defined the condition they had and the symptoms they were experiencing. This reinforced their ability to identify with the diagnosis attributed to them and their belief that the Rheumatologist was correct in their diagnosis and subsequent advice and management. With the provision of a diagnosis by a credible third party it appeared they now felt able to comply with

society's expectations of an 'ill person'. A diagnostic label provided them with an explanation for the "today I'm sick" (Frank, 1995 p.77) component of the restitution narrative and helped them to begin to understand why their bodies were no longer reliable and responsive. There was a justification for how they were feeling that they considered acceptable.

The provision of a diagnostic label with its associated legitimisation appeared to have significance to others as well as them. They had a medical 'label' which could be used on a sick note or by their partners to provide credible explanations for the experiences of the participants. Questions that had previously been raised about the validity of their symptoms and behaviour could now be answered. Requests for their family to help support them e.g. in asking for time off work, were now vindicated. A number of the participants had previously been unsuccessful in their applications for sickness, disability and carers' benefits. In this initial period following diagnosis they were hopeful that the newly acquired diagnostic label would provide the necessary validation for a successful appeal. This provided further evidence of the wider implications that diagnosis could have in enabling the fulfilment of the restitution narrative.

The important role that the acquisition of a diagnostic label provided was also manifest in the opportunity it provided to access information independently e.g. from the internet or the library. It equipped them with a definitive search term that had previously been denied: it had previously been difficult to search when all they had were non-specific signs and symptoms. Now it seemed that many of them began to feel that they could fulfil the expectations they believed society had of them i.e. to self manage, engage with treatment and do whatever was needed to 'get better'. Their stories now became tales that were embedded with the desire to once more enact the plot 'for every illness there is a remedy' (Frank, 1995). Participant 2 describes how she went home immediately after her consultation to find out what she could about her diagnosis:



"I got home and I looked up information on the internet. I wanted to find out what it was this fibro' and what I could do, how I was going to be"

With this came a growing awareness that much of the available information came from America and it was difficult for them to know what information to act on. It created the perception that in the words of participant 21 "they are more interested in it over there". They appeared to believe that the knowledge base and expertise in treating FMS was greater in America and that there was an improved chance of getting better if you lived there.

The participants also appeared to recognise that whilst they were in receipt of a diagnosis it was not a condition that was familiar to many in their social and work circles. This once more had the potential to place some of them in chaos due to the invisible nature of FMS in society and the effect this had on its credibility: this ultimately led many to question the stigma it might carry.

Following diagnosis the perception grew that this was not a condition that could be 'cured' but that needed to be managed. This did not however remove the desire to get well and throughout the period of this study the restitution narrative remained embedded within the illness narratives of every participant interviewed. The hope that one day they would be symptom free and able to return to their normal lives was voiced in each interview throughout the study and is highlighted by participant 4 in her first interview:

"I understand it can be pretty ongoing. It is possible to go away but it would be like magic if it went away. I'm quite positive thinking and I think it will go away"

Diagnosis had signified the hope of a cure which for all participants was never realised. In spite of this none of the participants ever said that they regretted being

given the diagnostic label of FMS. However, over time they acknowledged that being diagnosed brought 'new problems' which were linked both to the lack of definitive treatment and the illness identity associated with FMS.

#### **5.4.2.2 Hope of finding a cure**

Pivotal to the theme of being diagnosed was the sub-theme 'hope of finding a cure' that arose from the anticipation of treatment and an eventual return to normal. There appeared to be a perception that treatment would now for the first time be targeted on managing their specific diagnosis. However, for the participants in this study there appeared to be no universal pathway of care and heterogeneity was evident in the way they were managed. What was consistent was all participants were discharged following their initial appointment and no further arrangements for routine follow-up made. Results of any tests were sent to them and to their GP to manage if required. In this way, it seemed that the medical profession had adhered to its function in the restitution narrative and biomedical model of determining what was wrong. However, now it was unable to provide the anticipated cure and therefore failed to permit the end of the restitution story to be told.

All of the participants in the study received a review of their medication by the Consultant Rheumatologist: usually they received the prescription of a tri-cyclic anti-depressant which the majority understood would help with sleep and pain control. This seemed to provide further evidence that an attempt was being made to fulfil the restitution plotline by providing the notion of an externally derived remedy which would improve things and hopefully restore normality. A small number of participants however recognised this medication as an anti-depressant and were concerned this was a further attempt to fulfil the restitution plotline by psychologising their symptoms and managing it accordingly to get resolution:

"And they wanted me to take this amitryptiline but I'm not depressed, it's not in my head" Participant 23

As previously described the participants described how they were given the ARC information leaflet (ARC, 1999) and this gave them hope that the symptoms of FMS could be alleviated. This was supplemented by information that they quickly resourced themselves from the library, internet, books and other patients. Their traditional understanding of health being primarily a result of physical factors and accompanied by an appropriate remedy was challenged early on and caused ongoing conflict throughout the study. Many of them began to gain an appreciation of the role that psychological factors could play in FMS aetiology and management. They described how they began to consider the role that stress and depression in particular had in both symptom onset and management. This was evidenced in the first interview with participant 14 who intimated that the circumstances of her childhood may have contributed but did not want to disclose any thing further regarding this:

“‘I know it’s not in my head, but that stress can change how you’re feeling. I understand now that throughout my life I’ve got a lot more tense than I realised and because I got tense so much it became a habit. I had a very tense childhood so you’re walking round like this (*shoulders pulled up to ears*) for most of your life and I know that that can make your muscles ache and that can lead to fibromyalgia. I’ve started to listen more to my body now” Participant 14

Many of the participants and their partners had embraced the diagnosis and information given in the consultation and leaflet and initially felt almost euphoric that there was now an ‘answer’ to their problems. However, they then highlighted how after they had discussed their consultation with family, friends or their employers there were further questions they would have liked to ask. This was also combined with a perception that people with other chronic musculoskeletal complaints would be followed up and supported as needed. The initial compliance with the restitution model by the NHS of providing help in resolving their symptoms was then replaced with feelings that they were once more ‘alone and struggling to manage’ and perhaps no further forwards:

“..you feel like you're a bit in limbo. If I had arthritis I could come to the Rheumatologist as much as I need” Participant 1.

Failure by their GP to diagnose this complaint led the majority to doubt the ability of their GP to manage their symptoms. In addition some of them voiced concerns that their GP might continue to doubt their credibility. They feared they might be denied access to future treatments and the possibility of a cure. In this way they were demonstrating how they perceived their GP's to be 'gatekeepers' to the fulfilment of the restitution plotline. This once more highlighted the perceived difference between FMS and other 'normal' conditions such as arthritis.

A number of the participants were also referred on to the PMP or for physiotherapy. At this point the majority of these participants remained within the restitution narrative: they were hopeful that 'someone' would tell them what to do to get better.

Responsibility for recovery was being handed to third parties who had experience and knowledge of FMS. They discussed how they thought that once they had been for treatment they would be able to do 'the right things,' and demonstrated wanting to fulfil the restitution plot line and get better:

“They can make it easier for me to live with, they can actually tell me things what I obviously don't know or any kind of exercise which will benefit me in the long run. I know it's never gonna go away but they can make it easier for me to live with”

Participant 8

For a couple of the participants referral onwards returned them to chaos. They were unable to visualise how they could do what they thought was going to be required of them: they felt that they were misunderstood and expectations were being placed upon them that could not be fulfilled. It was apparent that within the restitution

narrative the NHS was attempting to fulfil the modernist expectation that for every ailment there is a cure but they were doubtful of the 'remedy' being prescribed.. It was also evident that some participants were accustomed to seeking health care remedies from other avenues. Once provided with a diagnosis they had begun to investigate alternative resources for information and treatment that might bring about a cure.

This is typified by participant 1 who showed a strong preference for the restitution narrative throughout the study. At the onset of symptoms and as soon as the potential diagnosis of FMS had been suggested by her GP she had searched for literature at the library that might help her understand and manage her symptoms. When this failed to bring about resolution she entered the chaos narrative for a short period of time whilst she awaited confirmation of the diagnosis. On receipt of this she continued to research the condition on the internet but also explored strategies she could adopt to fulfil societal obligations of returning to work as well as managing her symptoms. She negotiated a return to work part-time but also wrote a letter to her co-workers explaining the condition that she had, how it affected her and how it might manifest itself at work:

"Can you tell me more about the letter? What made you think of doing that?" CJD

"The admin team, the people I work with are aware of it because I work directly with them but the other people aren't. Some of them don't even realise I'm not there half of the time because I don't have much contact with them. They do their work but they don't necessarily come and see me. And I just thought I don't want to be going over my story with every single person in the office. There's about 40 it's gonna take forever. So I thought if I write them a letter I can just say this is what it is, this is what's happening please bear it in mind. If you want me to do something ask if I can do it I can, if I can't I'll obviously liaise with my manager and get somebody else to do it. Just to let people know what the situation was. I don't think most people have heard of it.

They go 'what?' Somebody said to me "how do you pronounce it?" He was happy with the letter but couldn't even pronounce the condition" Participant 1

This provided further evidence of the impact that diagnosis had on facilitating support and management once a legitimate label was given.

Following diagnosis, and over the course of the study, many of the participants had become aware of the local fibromyalgia support group. Some had seen posters in the hospital or GP practice, whilst others had been told about it or found out about it for themselves. Now they had a diagnosis they were able to access this group and there appeared to be two potential aspirations as a result of this. The first was that attending the group would give them the opportunity to find out more information about FMS and potential treatments. The second was that they could go and listen to the advice and experiences of other patients living with the illness.

It appeared that they hoped to go and hear restitution stories or if not those of quest. They described how they wanted to meet people successfully living with FMS, supporting each other and exposed to current advances in FMS diagnosis and management. What they feared was attending and being exposed to patients who were more disabled than them. They had a desire to be in a constructive and supportive environment but feared going and being with a group of people who complained rather than offered support. These typical concerns are voiced by participant 15 who considered herself to be a "positive and proactive person":

"I know there's a group but I don't know if I'll go. I don't want to just sit and listen to people moaning. If they really do support you that's okay. But a group of people just complaining – no thanks"

This describes the dislike for hearing chaos narratives and the societal preference for those of restitution.

At the initial interview there was knowledge that they might have this condition forever and that the future was uncertain. At the same time most of them described feeling positive about the potential for managing their symptoms more effectively although none of them had implemented any suggested strategies other than taking medication, that had been prescribed. The majority acknowledged that condition management was now dependent on them but all voiced, like participant 4, the hope that one day "it would just go away". They did not want to concede the possibility of a future with increasing disability and suffering and thus for the most part the restitution narrative remained forever present.

### **5.4.3 Daily living with an invisible illness**

The theme 'daily living with an invisible illness' became less synonymous with the restitution narrative as the period of "today I am ill" (Frank, 1995 p.77) became prolonged and showed little evidence of drawing to a close. Participants then appeared to show movement towards chaos and quest narratives which in themselves varied as to their dominance in the narratives. Restitution nonetheless remained constantly in the background. Attempts commonly were made, even with the passage of time, to explain their symptoms using a restitution narrative and the hope of an eventual return to normal and a cure being found never went completely.

#### **5.4.3.1 Trying to make visible the invisible**

The sub-theme of 'trying to make visible the invisible' highlighted the narrative preference in society for individuals to enact restitution. As the sub-theme 'the significance of diagnosis' has highlighted it is only by understanding and defining what is wrong with us that we can gain understanding from those around us and access to treatment. Being diagnosed appeared to help the participants make visible to them and others the presence of their illness, by giving them a label that could be 'seen' by others. It was visible as a diagnostic entity, a valid cluster of signs and symptoms that

initially triggered treatment, benefits and credibility. For example, this could be seen as a reason for being off work when written on a sick note or on a benefits claim.

All of the participants included in this study had to fulfil the ACR criteria (Wolfe et al, 1990) for diagnosis and therefore widespread pain was the dominant feature for all. However consistent with the typical clinical manifestations of FMS (Adams and Simm, 1998; Richards and Cleare, 2000), they also complained of fatigue and sleep disturbance. This was frequently combined with other symptoms including memory loss, poor concentration, clumsiness, an inability to 'find words', paraesthesia, depression and anxiety. All of these symptoms were invisible and unquantifiable to anyone but the person complaining of them. They were also unpredictable and variable on both a day by day and within day basis. Throughout the course of the study participants frequently returned to the restitution narrative as they described in detail the presence of symptoms and tried to manage them or understand how or why they had been aggravated. In addition throughout the study it appeared that they tried to make their symptoms more visible to outsiders by using metaphors to describe either the symptoms themselves or how they made them feel.

For the majority of participants the onset of FMS was characterised by pain felt initially in a single area. Consistent with the restitution plotline they frequently attributed it to a specific causative factor such as 'overuse', 'age' or 'injury'. They tended to use innocuous descriptions of their symptoms such as 'aching' highlighting their non-threatening and familiar nature. They appeared to be using language that others could use to understand what they were feeling and in this way seemed to be trying to make their symptoms more visible and discernible. Participant 4 described how she had initially attributed the initial pain to sleeping awkwardly and waking up stiff. However over time as the symptoms became more evident and spread she began to question her judgement about their presence and normality:



"So you just woke up and thought you'd had a stiff night or something. But when the stiffness got more and it was in both arms, you begin to think you know, you haven't done anything, you haven't fallen, you haven't had an accident. Something's happened to be both sides of your body"

In a similar manner all of them were affected by fatigue and non-restorative sleep. Their previous experience of fatigue/tiredness was non-threatening: they described how, before FMS, when they had been ill they would often feel more tired than usual or how tiredness was at times a pleasant sensation indicative of having had a busy day. These sensations were not just familiar to them but to the people around them. Their stories highlighted how initially they would search for rational explanations of why they were tired. At this time the tiredness was described using familiar and benign language to help others to 'see' what it felt like. This is typified by participant 18, when asked to describe what the tiredness felt like. She had previously worked, considered herself active and tried to explain the tiredness using her own perceptions of what was normal:

"I don't think you can describe it (*the tiredness*) properly, it just comes over you. You just need to go on your own and rest just to start feeling normal again. And in the beginning you do and you think maybe it's your age, that sort of thing"

However, when the fatigue and tiredness became associated with normal everyday life and there was no discernible cause the need to try and make people 'see' and understand how they were feeling became more overwhelming. This was usually manifest in the use of less benign language to describe their symptoms or how they made them feel.

Over time all of the participants began to question the explanations they were making as the pain and tiredness spread to other areas of their body. They were increasingly aware of the difficulty they had in gaining understanding of how they were feeling due to (1) the invisible nature of these symptoms and (2) the way they did not respond in a

normal way. Increasingly they appeared to begin to use more metaphorical language to highlight both how their bodies were under threat and perhaps to enable others to 'see' and understand what it felt like. This is typified by participant 11 in her second interview when describing her pain which occurs in differing areas of her body:

"It moves around, it moves around really it does. You know and you try and explain and it's like hot knives you know and the pain is absolutely, it's horrible. It's like somebody torturing you"

Continued attempts were made to enact the restitution narrative by searching for reasons for their new and increasing symptoms. They were however unable to do this and this began to facilitate a movement to either a chaos or quest plot-line.

The movement towards alternative illness narratives was further facilitated by the development of other symptoms commonly described by patients with FMS (Adams and Simm, 1998; Richards and Cleare, 200) and included clumsiness, poor memory, a global feeling of weakness, an inability to articulate clearly and poor concentration. They struggled to contextualise any of these symptoms as being normal for them and described how they might have been able to explain them if they had occurred in isolation. The combination of all the symptoms they were experiencing increased their inability to find a rational explanation for them and as they failed to resolve over time they described how they intruded into all elements of their physical and mental well-being. They were increasingly unable to fulfil the requirement to 'get better' and this again signified the movement to describing either a quest or chaos narrative.

#### **5.4.3.2 For every illness there's a remedy?**

As previously described, following diagnosis participants were discharged to the care of their GP. Within the second interviews it was possible to identify that participants 1, 5, 15 and 16, were still trying to predominantly fulfil the 'tomorrow I will be better'

(Frank, 1995) facet of the restitution story. Hope that their strategies would lead to a cure were evident alongside a growing realisation that true resolution was unlikely to ever occur, and this became more apparent in the third interviews. Participant 1 had self resourced treatment with a homeopath which she initially felt was helping to manage her symptoms, and as a result she declined a place offered to her on the pain management programmes. By the time of the second interview she was managing her symptoms in a way that allowed her to fulfil her own requirement “of being more than FMS”. She discussed how homeopathy had helped to alleviate her symptoms but emphasised how she considered much of its effect the result of the opportunity it provided to discuss strategies for symptom management at work and at home. The homeopath was someone she had confidence in, who could guide her in doing the right things that would alleviate her symptoms and restore some normality:

“And I have found going to the homeopath helpful. I don't really know whether it's the remedies. I mean we've been trying to work out what's helping and what's not. Different doses and different things. You don't know whether it's the talking. She's made me realise how stress makes me feel so much worse and we've talked about what I can do to help with that. You know home, work everything. Whether it's that that's making the difference? I mean it might be”

Over time there was a growing acknowledgement that her symptoms were going to persist and as a result the quest plotline then became more prevalent.

Continued attempts to enact the restitution narrative in the management of symptoms were also evidenced in the stories of other participants. This however became a subplot with quest or chaos now the dominant narrative being told. This typically occurred when traditional remedies had failed or when they continued to resource management strategies when NHS funding stopped. One of the most commonly resourced strategies was books purchased on the internet. This was done with a degree of scepticism, with participants highlighting the restitution stories that they frequently told.

Whilst these were the stories they wanted to hear they grew increasingly cynical about the reality of the evidence they contained and begin to consider that their pursuit of a remedy was misplaced. The books inevitably only helped them in the interpretation of the diagnostic label and in giving credibility to their experience, thus fulfilling part of the restitution plot line.

With a poor evidence base for treatment of FMS as a homogenous condition and what they considered to be poor levels of improvement more of the participants began to further explore alternative treatments. Their endeavours to find a remedy were most prominent in the early interviews but persisted throughout the study. Most participants utilised more conventional treatments which included massage, heat and TENS.

Participant 11 did describe how she utilised skills she already had as a Reiki master to bring about some alleviation of her symptoms. In a similar way participant 8 drew upon the knowledge she had of marijuana as a painkiller to help in the management of her symptoms. Her grandfather had found it beneficial in his management of pain he had when he was in the terminal stages of cancer. She discussed how she had occasionally used it to help her with the pain she was experiencing especially when her pain woke her at night:

"It does help me sleep a bit. I can wake up every single night about 5 to 3, and you know what sends me back to sleep? If I have a couple of puff, then I can go back to sleep. I have to come down for it. I have to come down for it, the dope, the marijuana. I know I shouldn't. But I did give it to dad when he was dying of cancer and he'd fall asleep in an instance....." Participant 8

"and did that help?" CJD

"It helped me sleep, a lot better than what I did before. But it also made me eat as well. So that was no good. Don't get me wrong if my husband can get me one (*a joint*) he will do but I don't want it in my house and the kids around it..... I can't say it can

recover me from this but it can make life more comfortable for me at night" Participant

8

She knew that what she was doing was illegal but felt that the benefit gained outweighed the risks. She argued that its use for people in pain should be legalised as it had the potential to help alleviate their suffering and therefore fulfil their social duty to get better. Without it she felt she was a greater burden on her family and society as she was able to function less well.

A few of the participants over the course of the study began to consider further whether addressing the psychological and social aspects of their condition would provide the elusive remedy. This occurred at different times and did not appear to be directly related to length of time of symptoms or time since diagnosis. They did however uniformly seem to show evidence of being able to consider that if addressing the physical had not resolved their symptoms then perhaps psychological management might. It is possible that providing these participants with the opportunity to tell their stories allowed them time to consider the influence that their psychological well-being had on symptoms and potential role on symptom management. Just as with those participants who were trying to use 'traditional' remedies to resolve their symptoms so they began to consider how addressing the psychosocial aspects of their illness might bring recovery.

This is typified by Participant 9 who described her symptoms beginning when her husband was ill, and how she had experienced his death and two others in her immediate family. She appeared to strongly suspect that her symptoms were a result of this and that treatment should perhaps address this:

"I thought it was just depression. I thought it was just to do with the running around. With regard to my husbands illness initially, because of his liver transplant 'cos his liver transplant was done in Leeds. So I thought it's probably the running around with

him, the running around with the children, the everyday chores that you do get tired. And then maybe it's stress and depression. I think as time passes that it's more to do with the stress and depression. And the GP she suggested I try anti-depressants, but I'd rather try counselling than that. I've had aches and pains before, but this is different. I'm sure it's everything else, you know to do with the mind"

Further evidence of the restitution narrative being presented to patients came from the experiences of those participants who chose to go to the FMS support group. New advances in FMS diagnosis and management were presented with some of the speakers (usually private enterprises) making suggestions of potential remedies that were available for purchase. Whilst this was encouraging it was usually interpreted with a degree of scepticism and had parallels with their feelings about information available on the internet. Concerns were raised about the raising of 'false hope' and the potential for profiteering from those with FMS who were desperate for a cure and 'willing to try anything'. Their experiences increasingly led them to believe that for this illness there was no remedy. This highlighted the conflict between continuing to want to hear restitution stories and enact them and a growing inevitability that this was unrealistic.

The participants also described how many of the patients who were vocal in the support group meetings had stories to tell of becoming increasingly disabled over time. They told of how once they knew who they were they tried to stay clear of them, as they wanted to deny the presence of the chaos narratives: they wanted to live with the hope that their story would have a 'happy ending' comprising either resolution or management.

Participants spoke in the interviews of their growing awareness of the desire for others (family, friends and employers) to hear a restitution narrative. In the early stages of their illness (pre- and immediately post-diagnosis) family, friends and employers would frequently ask how they were and 'were they any better?' This once more reinforced

the western expectation that when you are ill you get better. They often felt that they were failing to satisfy these expectations especially as time passed when they either didn't get better or improvements were quickly followed by deterioration. In contrast to many other chronic conditions e.g. diabetes, FMS did not have a recognised management strategy or external gauge e.g. blood sugar levels, to indicate how the individual was progressing. As a result, they often felt as though they were seen as deviant or non-complaint and found it hard to justify to others the lack of improvement. Participant 18 highlights this in interview 1 when talking about the difficulties she has sometimes articulating how she is feeling to her son:

"Can you tell me what it is about your son that makes you feel he doesn't understand?" CJD

"Well he's away in the army and he's not used to seeing me like this. And sometimes you're very good and sometimes you're very bad. And on the worst day you can hardly move. The thought even of getting a casserole out of the oven and cooking dinner. You burst in to tears when you are that tired. And he can't understand. 'Why are you like this?' 'Isn't there anything you can do?' 'Surely by now you should be getting better?' And you just can't explain" Participant 18

It was evident that the restitution story did not allow for relapses from the same condition especially when those relapses could occur within a day and showed no predictability.

#### **5.4.3.3 The loss of contingency**

The return of restitution as a dominant theme was typified by the sub-theme 'the loss of contingency' and the ability to once more take the body for granted. None of the participants in this study spoke of a resolution of their symptoms or a cure, but there was a minority (P1 and 15) for whom life began to return to what they considered

'some sort of normality' for limited periods of time. Restitution in its purest meaning was never fully realised for any of the participants but there were occasional moments when symptoms appeared to disappear albeit for short periods of time and predictability once more prevailed. For these two participants there was an acceptance of the presence of all of the symptoms of FMS within the framework once more of normal bodily experiences and these participants appeared to fluctuate between narratives of restitution and quest and only occasional chaos.

It appeared for these two participants that for much of the time life carried on as previously. They went to work, contributed in the house, and socialised. Allowances had to be made sometimes for their illness and how they were feeling, but this was interspersed with periods of time when life carried on as normal. Some of the time their life story appeared to carry on where it had left off prior to the onset of FMS and they had a strong hope still that one day life would return to normal. Just as 'normal illnesses' left their scars, these were often not noticeable most of time. This is highlighted by participant 15 in interview three:

"And you never forget it's there, but sometimes you can feel like it's gone, things aren't so bad. You have to be careful because sometimes it comes back to bite you. You've been carrying on like before and then 'wham' it hits you or you think blimey I'm aching again. I think it might be like when you've broken something, it mends but sometimes it aches and you realise something happened, you're not the same. But now some of the time I'm me again"

For these two participants it appeared that unpredictability remained but they had become accustomed to it. Additionally, the symptoms and the illness had become invisible once more and no longer needed to be seen all of the time by them and others.



## **5.5 Chaos**

The chaos narrative is typified by the theme of 'never getting better', a loss of control and the syntactic "and then and then and then" (Frank, 1995 p.100). The chaos narrative was present at some point in all of the stories that were told. For all of the participants this narrative first appeared to emerge when the symptoms of FMS failed to follow the modernist plot of "yesterday I was healthy, today I am sick, tomorrow I will be better again" (Frank, 1995 p.77. This realisation occurred at varying time points for the participants; they had individual expectations of how long symptoms should persist, what symptoms should be considered as normal and how they should be treated by the NHS and society as a whole.

The chaos narratives that presented throughout the study were dominated by the invisible and contestable nature of the illness, the lack of knowledge about it and how it permeated every facet of their lives. There was 'nothing to see' other than the physical and psychological impact of the condition. This was compounded by the perceived lack of knowledge about FMS in the health care field and ignorance within society as a whole. The condition had 'appeared out of nowhere' and they remained unable to find a rational and acceptable explanation. For all the participants in the study life was never the same again: however for those in chaos they 'grieved' for their previous ordinary life. The participants for whom this narrative dominated were P3, 10, 13, 17, 20 and 22. This wasn't the only narrative they told but it was most commonly in the foreground. For all participants the presence of chaos narratives were associated with the participants considering themselves as 'patients' and as a result the illness identity of FMS dominated their stories.

### **5.5.1 The battle to be diagnosed**

The onset of the chaos narrative was strongly linked to the theme 'the battle to be diagnosed'. When participants recalled their lives before the onset of FMS there had often been periods of apparent chaos but these had been short-lived. Previously when chaos had been evident it had been as a normal response to dramatic life events e.g.

child abuse, marital abuse, bereavement. Often these events had occurred on multiple occasions or in combination but from their stories it appeared that the participants had been able to 'make sense' of them. They had seemingly managed to integrate them in to their life stories. Chaos was suspended and they were able to return to their 'normal' and 'ordinary' lives. .

Chaos was initially evidenced for all participants when the symptoms they were experiencing failed to adhere to the usual model of onset, treatment and resolution. This was intensified by the continued absence of a diagnosis and they began to lose confidence in both their own and their medical practitioners explanations. This was highlighted by participant 8 who was accustomed to feelings of tiredness and bodily pain owing to the physical nature of her job. However she recalled how when these symptoms continued to return with increasing severity the justifications were inadequate:

"And some days I didn't feel it at all and other days I did. And as the years went on or the months went on and it was worse and worse and worse so I kept on going back to the doctor 'cos I weren't happy with what he was saying"

This was at odds with their previous experiences of illness. The search for a diagnosis to validate their experiences and symptoms became central to their illness experience at this time.

As with the restitution narrative the chaos narrative too became evidenced in the search for a diagnosis and treatment. Within primary care a number of tests were performed and treatments tried; sometimes these tests were initiated by the medical practitioner but on other occasions it was the participant themselves or their partner who suggested them. In the absence of any objective signs of illness and a diagnostic label there was a growing need for them to be able to find a physiological reason for their symptoms. Participants were plunged further in to the chaos when the tests were

negative or produced results that in time were shown to have little relevance to their symptoms. Initially they began to consider alternative benign diagnoses, but as time passed further chaos was evidenced as many began to consider the possibility of serious disease, and in particular cancer that might have been missed.

As time passed, and symptoms persisted a number of the participants (3, 4, 6, 9, 10, 16, 17, 19, ) were sent to other secondary care specialists prior to their referral to Rheumatology. These included neurologists, psychiatrists, orthopaedic consultants and physiotherapists none of whom were able to provide the longed for diagnosis or explanation for their symptoms. The syntactic "and then and then and then" (Frank, 1995 p.99) characteristic of the chaos narrative was particularly evident at this point. This is demonstrated by participant 6 when asked if he'd seen any Doctors other than the Rheumatologist who'd eventually diagnosed him:

"...and I saw my own GP and then a vascular doctor and then a neurologist. And they do these tests and then some more tests, and all the time you're wondering what next"

They recalled how they underwent further examinations and investigations that were considered further barriers to overcome. They described feeling angry when the lack of objective signs of illness or adherence to known patterns of illness made them feel that their symptoms were not taken seriously. Frequently they felt like they were being told that 'nothing was wrong with them'. Participant 6 continues to describe being examined by a neurologist who could not identify a cause for his symptoms. His experience exemplified how the absence of confirmatory test results made participants feel that moral judgements were made by others about them or that their symptoms were then being psychologised:

"...he thought it was a joke. You know everything was normal and so I'm lying I suppose" Participant 6

It was at this stage that they increasingly seemed to feel that their symptoms were being attributed to psychological causes or malingering and began to feel stigmatised by their lack of compliance with the biomedical model (Engel, 1977) and ultimately the restitution narrative. This further appeared to perpetuate the chaos narrative and the feeling that they had both lost control of the symptoms they were experiencing as well as the process of diagnosis and resolution.

The difficulty in getting diagnosed also influenced how the participants thought other people perceived them, particularly their employers, friends and family and told of the contradiction that they felt existed. People were concerned and wanted to help and support them as they tried to get a diagnosis and treatment, yet with the passing of time they felt less as though the same people were losing patience and belief in them. This made them feel less credible and as though people were judging the nature of their symptoms. Participant 21 was recently married and described how initially her husband had been very concerned with the increasing pain and fatigue she was describing and was supportive as she tried to get a diagnosis. However, occasionally she felt that he too wondered whether her symptoms were physical or psychological in nature, as the person he married became increasingly incapacitated:

"He (*her husband*) has always been really supportive. But sometimes, when I was complaining and we still didn't know what was wrong, I just felt that maybe he didn't know whether it was all in my head. Really I knew that wasn't the case but just sometimes there was a doubt there"

They described how living with their symptoms and being accepted as a credible patient was a struggle and the struggle to get a diagnosis personified this. This period of chaos appeared to be shorter for those participants (1, 5) for whom the diagnosis of FMS was suggested early on by their GP's. It appeared that the return to a potential restitution narrative then became possible i.e. once they had an indication of what might be wrong they could both stop worrying but also consider potential treatments.

For all of them the lack of diagnosis contributed to feelings of illegitimacy, lack of credibility and stigma. This was an unpleasant time and one over which they had very little control. They considered themselves to be fulfilling social and cultural obligations by attending their GP and being compliant with tests and treatments offered and yet their situation remained the same or worsened. As others increasingly seemed to doubt them, feelings of self doubt materialised. Participant 8, in her first interview describes how when symptoms returned with increasing severity the justifications given by she and others were no longer adequate:

" And some days I didn't feel it at all and other days I did. And as the years went on or the months went on and it was worse and worse and worse so I kept going back to the doctor 'cos I wasn't happy with what he was saying. And you begin to think he (*the doctor*) doesn't believe me. And then you start to think, is it me, is it in me head?"

The proliferation of chaos narratives was evident as symptoms increased and yet remained invisible and unpredictable. They could not be outwardly witnessed when looking at the individual or made visible by tests performed by the medical profession. When new tests were performed or specialist opinions sought chaos was reduced or temporarily suspended; at this time it appeared that the restitution narrative was restored. When these failed to provide any definitive answers the descent into chaos was recommenced. As time passed this was magnified by the worsening or addition of new symptoms:

"and you have this pain in your back and in your shoulders, but then it moves to your hips and your knees. And you think its' gone and it comes somewhere else, and on top of it all there's other things: you're memory, you're tired. And you rest, and you think that should do it. But it doesn't it's just the same, but changing all the time"

Participant 23

With the passage of time symptoms were increasingly misunderstood as they didn't respond as anticipated or occurred for no apparent reason. This further highlighted the chaos syntactic of "and then and then and then" (Frank, 1995 p.99).

### **5.5.2 Living with uncertainty**

Living with uncertainty was a consistent sub-plot of the chaos narrative. It was both symbolic and the result of a loss of control and credibility in many domains.

#### **5.5.2.1 Limitations of a label**

The diagnosis of FMS by the Consultant Rheumatologist initially suspended the chaos narrative for all participants. They had a diagnosis and with it came the hope of resolution. They were all provided with a medication review and some were given the opportunity to try some different treatments including physiotherapy and the pain management programme. In spite of this for a few participants (P3, 10, 13, 17, 20 and 22) chaos quickly returned. The consultation and the ARC leaflet (ARC, 1999) they had been given combined with information resourced themselves provided knowledge that there was no definitive treatment. Some of them appeared to interpret this as meaning FMS was 'incurable' and this denied them the opportunity to enact the restitution narrative. This interpretation was enhanced when participants following diagnosis recognised that there was no defined illness trajectory for this condition. Some of the participants seemed able to cope with the future that this might bring but others were thrown further into despair.

Over time the chaos plotline was further demonstrated as the participants realised the negative connotations that the diagnostic label of FMS carried. This was in contrast to what they had believed would happen and was considered to be a result of both the invisible nature of the illness and the lack of any known remedy. This was demonstrated by participant 18 in her first interview when she was asked about what she knew about FMS:

"I think it's a strange illness because it's incurable but you don't look ill. And I think that is why some of the doctors they don't believe in it"

They became focussed on the lack of credibility associated with the diagnostic label of FMS and on the doubts that this then raised about them. This interpretation appeared to arise from a combination of contact with health care professionals and information available in the public domain e.g. the internet or books. A few participants (P1, 4, 5, 6 and 15) identified this as a lack of understanding or ignorance, whilst others felt they were being judged. This judgement was mainly attributed to the fact that the symptoms were: invisible, lacking in a definitive diagnostic test, and a product of them being middle aged women.

"and they can't see what's wrong with you, and they can't find out what's wrong with you. And you think I bet they think 'here she is again, moaning, complaining'. And you get fed up of feeling like that, of feeling ill and having no-one believing you, no-one finding out what's wrong with you" Participant 19

Over time some of the participants felt 'let down' as diagnosis failed to bring with it the anticipated solution. They had hoped that once they had a 'name' for their condition they would also have a cure. Instead they were left in 'limbo' with a condition that continued to have an uncertain trajectory. There was no guarantee that anything would help and this plunged some of them into further despair. They felt like they were losing control of the ability to manage their symptoms and this appeared to create more unanswered questions and uncertainty rather than answers. This is typified by participant 20 in her second interview:

"You're managing with what you've been told (*the diagnosis and the ARC leaflet*) but what you're told is not enough to manage it...it's a catch 22 isn't it. You've had the diagnosis but you're in limbo. You don't really know how to manage it".

The limitation of being diagnosed with FMS also appeared to manifest itself in the lack of knowledge of the condition by family and friends. When they returned to work and home they were tasked with having to explain it. They were aware that people had heard of other musculoskeletal conditions such as 'arthritis', 'slipped discs' and 'trapped nerves' but few people had heard of this. When people did appear to have heard of it, it was usually because they knew someone who had it. This led participant 15 to question if this condition was so common why was so little talked about it:

"And I went back and I told people what I'd got, this 'fibro', but they'd not heard of it. I mean there was one person at work and she said she'd got it and she said she wouldn't wish it on anyone. And you wonder what is it and why doesn't anyone know about it. I mean arthritis, they all know about that"

This highlighted the invisible nature of the condition to them once more and its lack of presence in society. This further contributed to questions about the credibility of being labelled with FMS and the potential stigma it might carry.

#### **5.5.2.2 There is no remedy**

The sub-theme 'there is no remedy' was demonstrated within the chaos narratives when the realisation that all treatments tried or offered were concerned with management rather than cure. The knowledge that the modernist assumption 'for every illness there is a cure' (Frank, 1995) was untrue for FMS was, for many of them, unprecedented. Continuing to tell a predominantly chaos narrative during the study was then partly linked to the inability to come to terms with this.

At the onset of symptoms a number of treatments were trialled and at this stage they were predominantly focussed on treating the symptoms. The symptoms themselves were familiar and thus familiar remedies were reached for e.g. rest, painkillers and heat. At this point all of the participants had been anticipating a 'cure'. With the offer of each treatment came hope but this was usually followed by increasing amounts of



despair when they failed to bring about the desired outcome. Following the consultation with the Rheumatologist all of the participants received a review of their medication and some were referred to other agencies e.g. physiotherapy or the PMP. For the many of the participants this returned them to either a restitution of quest narrative.

In contrast a small number (P3, 10, 13, 17, 20 and 22 ) were plunged further into chaos by the prescription of medication that was licensed primarily for the treatment of depression. They interpreted this treatment approach as psychologising their symptoms. This was typified by participant 23 in her first interview when recalling how she felt when she was prescribed a serotonin based medication (at a non-anti-depressant dose of 20mg). It had been explained that this was aimed at improving her sleep patterns and that this might then help with her other symptoms:

"And they wanted me to take this amitryptiline but I'm not depressed, it's not in my head"

Further questioning reinforced that she was unable to understand that the role of this medication was in sleep regulation as opposed to mood enhancement.

Recommendations were also made in this initial consultation to increase their activity levels. It appeared that this advice was not questioned at the time and they discussed how they 'went along with the suggestion'. Many of them had previously taken part in exercise or wanted to lose the weight they had gained since being ill. As time passed they began to question this, as they contemplated and experienced the practicalities of this. They struggled to understand how they could exercise when activity exacerbated their symptoms. For the majority they were able to make a transition to where the quest plot dominated as they resolved the issues surrounding this. For the minority however it plunged them further into chaos as they were unable to fulfil this objective and often felt as though they did not even know where to begin:

"And I know it (*the leaflet*) says that exercise can help. I'd love to do it but how. Some days I struggle to just get out of bed" Participant 17

The presence of a chaos plot-line was further perpetuated as the participants grew increasingly frustrated. They grew disheartened by their interactions with medical and other health care practitioners who they felt were failing them. Medication prescribed failed to bring with it the desired and elusive 'cure'. In addition they felt as though they were repeatedly being asked to do things e.g. exercise that was beyond their capabilities. Alternatively they were asked to consider treatment such as physiotherapy, which they had previously undertaken with little benefit, and now was considered by participant 3 "just a waste of time". They felt they were then perceived as 'not trying' and this made them feel angry and/or upset. Feelings associated with a lack of credibility and stigma grew together with the feeling that 'no-one understood'. This appeared to further magnify their frustrations and lack of control over both how they were being treated and their life in general.

They felt that the information given in the consultation and leaflet was helpful, but what was lacking was the opportunity to discuss it once they had processed and reflected on it. They appeared to be lacking the skills to integrate this advice into their lives and quickly felt defeated when they did try and it didn't work. There seemed to be a growing feeling that every thing they tried failed and nothing was going to work: "and you do what they tell you, you take the tablets (*citalopram*). They don't do anything, nothing does. And that leaflet says to exercise-well how can you do that? When you feel like this. And you can't go back. Discharged – see your doctor. Nothin' more they can do. And I read the leaflet – and that's it. This is how it's going to be. No cure, just this" Participant 22

For the majority of participants (even those who were now telling a predominantly restitution or quest narrative) chaos remained in the background; initial feelings of

having help to resolve their symptoms once more gave way to feelings that they were 'alone and struggling to manage'. The belief that this was a condition with no remedy became embedded within their lives.

#### **5.5.2.3 An unpredictable and unresponsive body**

As time passed the chaos narrative was further typified by stories where contingency was prevalent and the loss of predictability mourned. This inevitably affected all participants at some point in their illness experience, although for some it was more transient than others. They told of a body over which they had little or no control; pain, fatigue and physical functioning occurred independently and in spite of them and their actions. Chaos was evidenced by the presence of unusual symptoms or those that occurred in the absence of any recognisable cause and/or failed to respond to usual strategies. Symptoms permeated multiple parts of their body and their lives. There was an emphasis on the 'invisible' nature of their symptoms and their unquantifiable nature, compounded by their changing presence on both a day to day and within day basis. They frequently felt at the 'will of the body' which had become a stranger to them and just appeared 'to do its own thing'. This was typified by participant 6 as he described his consultations with his GP about this:

"They (*his legs*) were aching all the time and I kept saying to the Dr 'me legs ache doc'. It's like I've run a marathon and it's not right"

The chaos caused by their symptoms was most evident when strategies to manage them failed. The prevalence of this narrative varied amongst participants both in time scale and frequency. The movement towards a quest or restitution narrative appeared to be accompanied by the use of successful management strategies or acceptance of their symptoms. However, In spite of their best efforts there were times when all attempts to successfully control or accept their symptoms failed and chaos returned.

A number of participants (P3, 10, 13, 17, 20 and 22) were unable to reconcile themselves to the effects of FMS. They appeared unable to overcome or integrate the unpredictable, debilitating and invisible nature of the symptoms within their lives and they demonstrated features of being defeated, outraged and depressed within their stories. Participant 20 demonstrated this when she described how it had affected relationships with her children. Her son and daughter had both left home and regularly visited to help her. However, she often felt frustrated by their apparent inability to comprehend how she was affected:

"So how does it affect the relationship with your children?" CJD

"Because you're nasty aren't you? You don't think they understand. You see I can get up one minute and walk in here and I'd be fine, and then I'd take a turn and I'd think 'oh' and I'll have to sit down. And he'll say 'go on make a cup of tea' and I have to say 'I can't I'm in that much pain'. And he'll say 'but you moved a minute ago'. And then arguments will build from there. I'll blow" Participant 20

Chaos and a loss of control over how their bodies felt was evidenced in the metaphorical language that participants used to describe their symptoms at different times. When contingency was present descriptions indicative of bodily harm being done to them were used such as 'burning' and 'stabbing'. Descriptions appeared dramatic and out of context in the absence of trauma or tissue pathology. In her second interview participant 20 described the pains that she experienced in her legs and was unable to control. She described how she questioned herself and whether her symptoms were due to FMS because of their severity which she considered unusual given their nature:

"Is it the fibromyalgia that has caused it... because the pain is so severe? It still wakes you through the night. It's got worse; it's attacking my legs and my knees give way.

The pain gets so severe. I had a fall and I went to the doctors but he just said it's the fibromyalgia"

This type of description appeared to be used to give emphasis to the experience of the pain and how it felt like their body was 'under attack' or 'broken'. Throughout their interviews when a chaos narrative was present the use of this type of language appeared more common, and indicative of a body that was no longer predictable and responsive. The chaos narrative also appeared to be represented by reactions to the symptoms that to an outsider (myself) were out of context. This was typified by participant 14 when describing pain she had in her hip. She described this pain as being so severe that she had attended an accident and emergency department because she thought she had somehow damaged it, although she could not recall any trauma:

"When I had the hip problem I found that.....I wore another pair of shoes that were quite hard based. And I found it was painful and I went to the hospital because I didn't know what the matter was. It hurt putting weight on it" Participant 14

"Why did you go to the hospital and not to your GP?" CJD

"Because it was so painful and I thought the GP would just refer me to the hospital anyway. I wanted some relief and I thought 'have I broken it? Have I sprained it? Have I twisted it? I just don't know. And you feel okay one day and not well the next. And I can't see anything that's the matter, but it's like something's happened, but you don't know what" Participant 14

"And what happened when you got there?" CJD

"Nothing. Not even an x-ray. I wanted to know what's wrong. But they said it's nothing serious. You've not done anything, you're well. Go home and heres some painkillers.

See your GP if it doesn't get better. But you know the next day it'll be gone or moved somewhere else" Participant 14

Alongside pain, fatigue was another common symptom and this seemed to heighten the loss of predictability that was often felt over their bodies. It appeared on its own less distressing than the pain but the cumulative effect of fatigue and pain seemed to heighten the pain experience. They mourned the inability to sleep and described both the loss of quantity but more significantly the quality of the sleep they desired. When they were tired their bodies did not respond in the normal way and sleep did not come easy to them. This was highlighted by participant 19 who worked shifts as a nursing assistant:

"I'm tired all the time, I can't sleep, I live on 2 hours sleep a night. As soon as I get in from work I go straight to bed, but I don't sleep. I just lie there.....If I'm not at work I'm in bed, just tired all the time. I've got amitryptilline still and had my dose up to like 30 instead of 10, but that still don't work"

The lack of response to strategies that would ordinarily have resolved fatigue was evident here as was the syntactic of 'and then, and then and then' that typifies the chaos plot line.

All of the participants described how they became tired doing things that previously would not have bothered them. The tiredness that they felt was disproportionate to the physical effort that they had put in. This defined it as symptomatic rather than symbolic of being busy and leading hectic lives. This initially plunged them into chaos as they once more lost control of their bodies and lives. It made a number of them feel old and was characterised by participant 10. She described how she would feel "physically exhausted" going up the stairs at work (in a hairdressers) and yet her elderly clients could ascend them without difficulty. They identified how previously they might sometimes consider tiredness a pleasant sensation indicative of having had a busy

day. Now it was associated with feeling unwell: this was reinforced by the feeling that they rarely had any moments when tiredness was not present and no ability to control it.

The quality of the tiredness was also different and it appeared to have a whole body and all consuming nature to it. This further characterised it as different to their 'normal' experience of tiredness. They reflected on how before FMS tiredness was a feeling that might affect either their whole body after a busy day or a specific body part if they had been over-exerting themselves. Now the tiredness was variable and unpredictable, and did not respond to attempts to alleviate it. There were frequent recollections of how, prior to the onset of FMS, if they were tired they would try to take things easy or get to sleep earlier and inevitably within a day or so they would feel better. Now these strategies failed to bring about any significant change and at times might even make them feel worse.

For those participants where chaos was the dominant narrative they were unable to regain control of this. In contrast those that were able to move into the other narratives were able to move from a position where this prevailed to one where they regained some predictability over their bodies or accepted the unpredictable nature as predictable.

As with the experience of pain they also used metaphorical language to contextualise the tiredness and try to convey to others what it felt like. Participant 14 highlighted how the tiredness created a 'struggle' to move through the day:

".. and tired all the time. Getting up in the morning feeling tired is dreadful and you feel like you are in a batch of treacle and can't get out"

Language such as 'exhausted', 'heaviness', 'burnt out' and 'the need for rest' were commonly used to convey how the tiredness made them feel. They expressed the

difficulty they had in getting others to understand how they felt, to truly appreciate how being constantly tired made them feel and this was magnified by the inability to identify a causative factor. It was at these times they appeared to use metaphors to try and achieve a level of understanding and empathy. If control was not regained and there was a continued absence of understanding by both themselves and others there was typically a descent into further chaos.

Chaos was also heightened with the onset of other symptoms which they were both unable to explain or over which they demonstrated little control. This was once more an example of the loss of predictability of their body and heightened the sensation of a body spiralling out of control. The nature of some of these symptoms in particular contributed to the presence of contingency with respect to their bodies and their lives. For some of the participants this was transient as they evolved strategies to cope and moved into a quest narrative. For a minority they never adapted to these symptoms and they combined with the pain and fatigue to produce a magnified effect. This was typified by participant 12 in her second interview:

"and sometimes you're so tired and everything hurts. You don't know what to do with yourself. You try to sit and watch TV but you can't concentrate, and then you can't remember what's happening. It all just tires you out"

Poor concentration and memory were described by all and contributed at varying times to feelings of frustration and 'uselessness' reinforcing the perceptions of an unreliable and unresponsive body. They described deterioration in cognitive function at home and/or work and these were magnified when they were tired. Chaos was also evidenced by feelings of 'weakness' described by the participants and was once more linked to a loss of control and normality. This had two dimensions: there was a notion of loss of power and an inability to perform normal daily tasks leaving them frustrated. This led to feelings of loss of control and of no longer having an 'ordinary life'. There was also a global feeling of weakness which was used to describe a 'whole body



tiredness' and their perceptions of themselves as 'weak individuals' unable to cope with the normal challenges of life.

There didn't appear to be a uniform threshold at which this infiltrated their lives or predicted whether they would remain in chaos or be able to move into another narrative preference. The effect of this was highlighted by participant 6 who throughout the study mourned the growing inability to rely on his memory and concentration. Much of the time he was able to tell a quest narrative once he'd been diagnosed. However, he was plunged in to telling a chaos story line when he recalled his inability to perform tasks he had previously relied on his body to be able to do. He had previously enjoyed wood carving and doing DIY at home and began to feel growing feelings of inadequacy at his inability to fulfil his duties at home:

"...my memory was useless, still is, getting up in a morning, well my wife comes shouting at me just to keep me on my toes. Everything seems to be a struggle to do, you want to do it but you can't. I can't concentrate. I've started jobs at home but I can't get into it like I used to. And I've got a good girl, and I'm letting her down"

Characteristic of the all participants who appeared to demonstrate a preference for the chaos plot line, this highlighted a feeling of being overwhelmed by their symptoms. There was an intrusion into all elements of their physical and mental well-being. They felt 'trapped' by their symptoms and that their body had been 'taken over' by this condition and all its' manifestations. This in turn appeared to create feelings of being old or 'worn out': their body felt useless and this contributed to them feeling useless too.

#### **5.5.2.4 A life out of control**

Chaos was also evident as a plot-line in the stories of participants whenever there was an apparent loss of control over life and increasing isolation. For some this was short lived when symptoms returned unexpectedly but for others it was a more dominant

theme. At these times it appeared that participants described rarely leaving the confines of their home environment and this appeared to contribute towards making them feel alone in their illness experience. The unpredictable and debilitating nature of their symptoms made it difficult to plan their life in the immediate, medium and long term. The life they had envisaged now and in the future was no longer visible. As a result they either struggled to visualise how life would be or saw a life that seemed unpleasant.

For those participants where chaos was the dominant plot line they were unable to return to work and showed little if any evidence of having social support. They described families that, if still in contact, were at worst sceptical or at best divided in the support and understanding that they were able to offer. None of them had a partner and only one had children still living at home. Their encounters with health care were dominated by feelings of their stories being denied, with insufficient time and tolerance bequeathed to them. This was consistent with the early perceptions I had from talking to health care staff who considered this group of patients as 'heart sink' patients; these patients were 'dreaded' and considered as always seeking treatment but never improving.

Evidenced in the stories when chaos was dominant was the notion that life was not fulfilling for this group and that they had lost control over their life history. The life they had envisioned for themselves had not looked like this. They had lost their jobs or plans for work and with this financial security. This in itself contributed to the spiral of further chaos. With a loss of income came added pressures and for two of these participants (P10 and 13) the potential loss of their homes.

This is highlighted in interview 3 with participant 13 who as a result of her illness had experienced marital breakdown, loss of her job and now was wondering whether she could remain in the apartment she had moved to but was now struggling to afford:

"And you said this wasn't how you'd imagined how things would be. Can you expand on that for me?" CJD

"Well you don't do you? I had my job and I lost that. And as I said my husband didn't understand, thought I didn't love him, and he left. And then the kids. My daughter understands and comes round but not my son. He doesn't understand and I don't get to see my grandkids, and it's not how you imagined things. And then you wonder, how long can I stay here? They took it away (*the higher level DLA*) and they don't realise how much you need it, how much you've lost" Participant 13

Benefits were applied for but this further exacerbated the chaos and loss of control. Often benefits were denied and there ensued a struggle to try and maintain an income that would sustain them. This also reinforced the belief that 'no-one understood' and 'no-one could help' their situation. Income was often seen as a means to facilitate coping with FMS and regaining some control over their lives. With extra income they envisaged that they would be able to purchase outside help such as a cleaner, get out more by paying for taxis, or purchase aids and adaptations that would make life more tolerable e.g. mobility aids. With the prospect of financial assistance thoughts of a different life were restored only to be relinquished when they were not forthcoming.

Alongside the frustrations of not receiving benefits they appeared to be frustrated at the lack of understanding the people administering help and benefits seemed to have. They spoke of how these external agencies did not seem to appreciate the control they had over what they were able to do with their lives. There seemed to be an overriding emphasis on 'the system' failing them and not having empathy with their situation. This is highlighted by participant 14 in her second interview after she had been describing how she had begun a customer service training course and her incapacity benefit had been stopped:

"So what's the motivation behind the new course" CJD.

"Well I've come off the incapacity. And I feel I'm in between the two which is an awkward place to be because you're not fully well but you don't think I'm bad enough to be incapacitated. I want to be independent and make more money. When you work and claim benefits they more or less control your life; 'you have to attend an interview or we won't pay you' kind of thing and 'you have to do this'. Nobody wants that. And it's not your fault and you want to do what you can, but they can't see that sometimes you just can't do it. It's something else that you can't do anything about"

Their stories frequently told of how life could be if "they had less pain" P17 "had more help" P13 or "were able to get a job" P3 but there appeared to be a lack of desire to influence and enact this. They appeared to be passive recipients of life denying the role that they had in the story that could be told. Control had been relinquished and they were at the will of their body and life events. Whilst they continued to demonstrate health seeking behaviours i.e. repeatedly visiting the doctor, they also appeared to have given up hope of ever getting better and life returning to 'normal'.

For participants telling the story of chaos it also appeared that they had not come to terms with the loss caused by FMS. Whilst most participants had led what to an outsider appeared to be chaotic lives prior to the onset of FMS the over-riding emphasis was on a past and present that had given a glimpse of a promising future. They were able to describe how they had previously been able to overcome adversity but faced with FMS this appeared impossible. A reliable body and dependable present and future were now denied to them and they recalled the lives they had envisaged living. Now when they contemplated the short and long term future it was multi-faceted: hope remained of an eventual return to normal when a 'cure' was found; a future was occasionally described consistent with literature they had read depicting the worse case scenario for FMS and chronic pain conditions; or the future was denied appearing mindful of the need to protect themselves from further chaos if it failed to materialise in a way they would have liked.

This is characterised by participant 11 in her second interview:

"For many years I used to earn a lot of money as I used to work for social services and then I had a business of my own. And I had a bit of money and I bought a house in France for my children – only a small thing. They've never bothered with it. I was going to retire there. My son is a tetraplegic, he's been in an accident about 20 years ago and when I was working I cared for him. He phoned me and said 'mum, why don't you just go over to France and live over there?' And I said I would if I could but I can't afford it now I can't work. And how would I get over there? But the thing is he said I might be better over there, they've got a better health system. But I don't want to be left out on a limb, not like this"

Chaos was further evidenced when participants developed new health related symptoms and problems. There was a perception amongst the majority of participants when once diagnosed with FMS it was more difficult to convince health care professionals that they had other illnesses. They appeared to feel as though they were no longer treated the same as other patients. Participant 14 characterised it as becoming a "get out of jail card", an umbrella term that was used to "fob you off when you had new problems". Chaos was perpetuated by the reluctance of health care staff to take them seriously and this led them to describe how they had lost control over their health.

In some instances further investigations were neglected and for participant 18 this led to potentially life threatening consequences when she began to complain of increasing fatigue. At her second interview she described how initially these symptoms were ignored but when she eventually became jaundiced, further tests resulted in a diagnosis of haemachromatosis. This delay in diagnosis had probably contributed to permanent liver damage:

"I didn't disagree with the fibromyalgia as it means I've still got it. But it is the other illnesses you can have with it. And I think they start to push other things going wrong aside because everything is...fibromyalgia. But there are obviously times when people have got other things and if it is going to be overlooked in some cases it could be fatal"

It appeared that there was a predominance of chaos narratives amongst those patients who were subsequently diagnosed as being depressed and this may have been to satisfy the modernist need to have an illness that can be fixed or mended. However, contingency that extended to other dimensions of their life was prevalent for those participants in chaos. From the stories that they told of life before and after the onset of FMS their lives had been troubled by events and circumstances which in themselves appeared 'out of the ordinary' and indicative of potential suffering. These were consistent with what Frank (1995, p.112) describes as a "life of overwhelming trouble and suffering". For example, participant 20 recalled the death of her son in a motorbike accident and participant 3 told of a history of child abuse.

Stories of apparent suffering before FMS were not however confined to this group (although all those with a dominant chaos plot-line told similar stories). A few of the participants with other dominant narrative typologies also disclosed similar stories of for example spousal abuse or unexpected bereavement. For all of the participants the types of events described were beyond their control. For those participants who descended further into chaos and appeared to be unable to move out of it, the advent of FMS and the contingency that prevailed over their bodies seemed to be 'more than they could bear'. Treatment and attention to their stories focussed primarily on FMS and its prevailing symptoms. If the attendant psychosocial influences on their life were heard, they were rarely listened to and there was an overwhelming feeling that something else outside of their control had happened to them, leaving them exhausted and unable to move forwards.

It is possible that these feelings contributed to all of the participants at some point in the course of the study describing how living with FMS had made them “feel down” P5, “depressed” P9 or simply “fed up” P21. They all emphasised that this was not the cause but the result of their symptoms and was attributable to the experience of ‘being worn down’ by the constant feeling of tiredness and pain and once more the loss of control over life and their symptoms.

This feeling of ‘mental suffering’ was at its height prior to diagnosis and increased by feelings of stigmatisation and concern about what was wrong with them. Throughout the course of the study a small cohort of participants (P10, 13, and 17) disclosed having suicidal thoughts and this appeared to be due to a perceived lack of control in their lives. Not only did they have to contend with the symptoms of FMS but they also had to cope with other stressful events taking place. There was for example the breakdown of relationships, the loss of employment and financial insecurity. When the combination of these events became too great they described how they would have difficulty in being able to visualise a better future. Despair then led them to consider taking their own lives.

Participant 17 had been living in a hostel following the breakdown of an abusive relationship. She had then begun with the symptoms of FMS and lost her job. She describes how it had affected her mood in her second interview:

“And you mentioned the fact that you weren’t coping. Can you expand on that for me and tell me how you weren’t coping? How did it affect you?” CJD

“I just felt useless, felt really, really low in mood. I felt no good to anybody. You’re not are you if you’re in that much pain you can hardly move. What use are you? And I did feel suicidal at one time. That’s how bad it got me” Participant 17

Whilst three of the participants (P3, 17, and 20) had previously experienced problems with depression, for the other participants telling chaos narratives this was a new experience. For those telling predominantly chaos narratives there was a sense of 'giving up' on attempts to control their symptoms and resignation to a life lived with FMS where it controlled them. They paradoxically handed over responsibility for managing their symptoms to others, in particular those in the medical profession, although they had done little to alleviate their suffering. This appeared to be consistent with the desire to tell a restitution narrative i.e. continued hope of a cure/of someone else making them better but was inevitably accompanied by disappointment when this failed to materialise.

### **5.5.3 Changing visibility**

The theme 'changing visibility' appeared to be representative of chaotic plotlines especially as time passed and they lived in the continued presence of the symptoms and diagnosis of FMS. Having FMS seemed to dominate their lives and be indicative of a process of loss of themselves over time. This was also accompanied for the most part by a gradual reduction in social contact and increasing isolation. For many of the participants describing other narrative typologies the feeling of being invisible was sometimes evident in the background and was more noticeable when their symptoms had worsened and/or were being poorly controlled. Their normal self would then be subsumed once more by that of the body and self with FMS.

#### **5.5.3.1 No-one to listen**

The sub-theme 'no-one to listen' described the reluctance participants felt was present in both health care professionals, their family and friends to hear about what was wrong them and how they were feeling. Initially they had found a receptive audience willing to listen to how they were feeling and what their concerns were. This was maintained when they were initially diagnosed but diminished as they failed to gain improvement or regain control over their lives. As the presence of those willing to listen diminished they increasingly felt as though they became invisible.



They spoke of the glimpse of interest in their stories they had felt when they had seen the Rheumatology Consultant. Here there was someone who took the time to listen to their descriptions of how they were feeling and believe them. This feeling however was short-lived when they described being discharged after their first attendance. For all participants there was the emergence of chaos as they realised they were being denied the opportunity to talk. They vocalised how they felt that this ability was conferred to others with different musculoskeletal conditions such as arthritis. Those participants who then went on to tell predominantly quest storylines were able to reconcile themselves with this and understand the rationale for it. For those who predominantly told a story of chaos this was absent and they continued to revisit how medicine in particular continued to deny them further opportunities for their stories to be heard.

Once diagnosed chaos narratives were dominated by stories of how when they went to see their GP they didn't appear interested in listening to their plight. They considered that were 'fobbed off' with medication and failed to appreciate the impact that FMS was having on them. This group appeared to fail to fully engage with treatment either through choice i.e. choosing not to go or take medication, or by not being referred or offered medication changes.

When they did engage e.g. as in attending the PMP they highlighted the benefit of being able to share their stories. Once discharged however, unlike participants who had moved into quest, they appeared reluctant to maintain relationships and opportunities to talk. They described how other members of the group were meeting up and how this opportunity had been extended to them. They then gave many reasons why they were unable to do this e.g. the cost or lack of transport and how they were feeling. They appeared to be denying themselves the opportunity to engage in something that they had described as very beneficial and seemed unable to overcome these perceived barriers:

"You said that you still talked with people from the pain programme. Can you tell me more about that?" CJD

"Well when we finished we said we'd meet up. You know to have someone to talk to, who understands. But I've been once, but sometimes it's hard to get out get on the bus and then walk. I could take a taxi, but I've not got the money. So one of them has offered to get me in the car, but you don't want to put them out. So I've talked on the phone, but not made it again" Participant 13

This group of participants also continually told of the apparent reluctance of their friends and especially their family to listen. They struggled to understand why this might be and gave the impression of feeling let down by the people they felt would be most understanding or supportive. The perceived aversion to listening was manifest to them by these individuals no longer visiting, or calling or not doing so as often. When they did come they told of how they appeared to be disinterested in what they had to say. They felt they would often be denied the opportunity to talk about their illness as whoever was listening changing the subject. The disappointment they experienced as a result of having no-one to talk to and listen appeared to be important to them and was discussed repeatedly throughout the study. They could acknowledge that listening to descriptions of how they were feeling might be unpleasant. At the same time they strongly felt the need to share this; it showed that others still cared about their well-being and somehow dissolved some of the burden of being ill that they felt.

#### **5.5.3.2 Stigma and identity**

The sub-theme stigma and identity showed strong associations with the theme changing visibility and the chaos plotline. Within this narrative typology stigma appeared to be accompanied by a change in identity, where the new identity was one which was begrudged and resented. In the initial period following diagnosis there were a few participants (P3, 10, 20, 22) who immediately seemed to perceive life with FMS as one where pain and fatigue would dominate and be uncontrollable. This seemed to

be indicative of a predilection to remain within the chaos narrative. Their interpretation of FMS was of a condition where the future was inevitable and consisted of a downward spiral of both their symptoms and their lives. They saw themselves failing to return to the people that they once were, and continued to wish to be, and this was typified by participant 20 within her first interview:

"This is what I've got, and I know it's not going to get any better. I'm going to get worse and I know I'm not going to be able to do things for myself"

Their previous identity, for example of being individuals who went to work, supported the family and participated in a social life, disappeared and was no longer visible in the present or future. They had diminished control over who they were and they relinquished themselves and their life path to being at the will of FMS and at the will of their body.

Those participants for whom a chaos plot line became dominant also appeared more ready to either adopt or seek out the label of being 'disabled'. Evidence of this appeared to present in two ways: one was the willingness to describe themselves as disabled and want others to confer this label to them; the other was the description of behaviours that demonstrated withdrawal from activities and societal obligations that would align themselves with the identity of someone being disabled. This was typified by participant 10 in her third interview when describing the support she gained from her faith and going to church versus the lack of support she had from her family:

"I've had some days when I've barely had the energy to go to church. But I know when I get there they'll understand. I can't sit in the seats for very long, but they know and someone will have cushions and it's better. They're used to it; not just me, other people who are disabled. But my family, I've got three sisters, one's a nurse, they just don't understand. It's come on P10, you can't sit around like this, you've got to do

things for *her son*. And so you just stop bothering. What's the point in them coming round? You feel worse when they do, so it's better to be on your own"

Being conferred with the label of 'disabled' appeared to give permission to become more visible in some circumstances and less visible in others. Within their home their continued physical presence meant they were more visible but this was contrasted with disengagement with household duties and social activities with the family. Thus they often perceived themselves as unseen.

A number of the women gave descriptions of their appearance that was further evidence of a changing identity and visibility. This was present in the initial interviews but manifested itself more as the study progressed. They spoke of how the onset of FMS had resulted in them gaining weight and becoming less active. Clothes no longer fitted them and they had lost the confidence to wear the same things as before. This was combined with the physical symptoms of FMS causing them to feel older than they were and resulted in them feeling unattractive to themselves and others, especially partners.

Once more they appeared to be describing a loss of control over what was happening to them and the loss of their identity as women. For those women in physical relationships this then began to impact on the physical relationships they had with their partners as they lost confidence in themselves. The syntactic of and "then and then and then" (Frank, 1995 p.99) typical of chaos was present in their descriptions of this. Participant 8 demonstrates this in her second interview when I asked about difficulties she'd described in the relationship with her husband in the first interview:

"Last time you mentioned that the pain and how you'd put on weight had caused some friction between you and your husband. You didn't feel as attractive and this was causing you problems with your physical relationship" CJD

"When we went out last week he said 'you look ever so nice' but I thought 'rubbish'. Every night before we go to bed he'll give me a kiss and say 'I love you duck' but that is the only bit of affection we show each other now. The affection has gone. He doesn't try and have sex any more. I want us both to do it, but I don't have the urge to have sex. And if you've lost that you've lost everything. Then you think well, what am I here for. You get frustrated and just think well, what's the point. And then you're like this, no sex drive and no proper marriage. That part of your life is gone"

It appeared that living with FMS had caused them to feel less visible as women, both in their own eyes and in the eyes of others.

Over the course of the study the stories many of the participants told alluded to the stigma of living with an invisible, unpredictable, disputed condition such as FMS. When this initially manifested itself the participants were aggrieved and of the opinion that society was making judgements about them as individuals. They felt that these views were made on the basis that unless you had a condition that could be seen, didn't change frequently and could be proven, it didn't exist or had dubious credibility.

The subsequent movement towards telling of quest or restitution was then accompanied by an acceptance that this was the view of a section of society. It was highlighted how they could almost align themselves with them, as sometimes they too found it hard to believe the variability of the condition. They knew that they were credible individuals and therefore they were able to reposition themselves with an identity that acknowledged this.

For those that remained in chaos or frequently returned there this was not possible. They seemed to feel persecuted and could not understand why others doubted them. Descriptions were often given of how they were not taken seriously or even at times felt as though they were mal-treated as a result of having FMS. Examples of this were most noticeable when these participants described their encounters with the

employment or benefits agencies, or with the health care system. Barriers to gaining support from external agencies were not universal to all who sought them, but chaos caused by perceived stigma was frequently evident or manifest on these occasions. This is demonstrated by participant 11 when describing how she felt when she had an exacerbation of her symptoms and tried to get a home visit from her GP:

"It's because people don't know what goes on behind a closed door and if you tell them they look at you and say... they think you're making it up. That day when I rang the doctor the receptionist thought I was an actress or something and I really felt as if I was going to die, I felt that ill! I felt as if all my systems were closing down and all you could get out of them was 'oh, you'll have to come down'. My language was rather strong to myself and I thought 'f you' and I just slammed the phone down. I did eventually get there but not until I could actually get myself together in to the car and I nearly had a smash in the middle of long eaton" Participant 11

"And where did you get the strength from?" CJD

"I just thought do I really want to sit here and die or do I want to attempt to get in to the car and do something about it. And it took me ages to get in to that car. It took me ages to walk down that bloody path and it nearly killed me and when I got to the end of it I was nearly crying. But nobody knows and nobody gives a damn" Participant 11

Moving back out of chaos into the other narratives was influenced by their ability to acknowledge that whilst sometimes they could control their symptoms this was not always possible and was in fact 'normal for FMS'. This was accompanied by an ability to regain belief in their own identity and become less influenced by what others thought. This aptitude appeared to either be elusive or impossible to come to terms with for those who remained in chaos. Life was miserable and an improved future remained out of sight.

## 5.6 Quest

The quest narrative is characterised "by the ill person's belief that something is to be gained through the experience" (Frank, 1995 p.115). The restitution narrative is typified by stories where illness is transitory following the taking of a remedy or adherence to a treatment regime. Chaos has been similarly characterised by stories where the illness remains, life never returns to normal and a loss of control is all pervading. In contrast, the narrative typology of quest is highlighted by stories that tell of lives where illness no longer remains but lives are forever changed or an alternative way of living with illness has been found.

In this study it is proposed that the quest narrative featured strongly in the experiences of most of the participants when describing how they lived with FMS. This however was not at the exclusion of the other two narratives. As previously described all participants continued to have the desire to enact the restitution narrative but for many this narrative was absorbed into the background as the dominant plotline became one of suffering that is not controlled or eradicated but 'just is'. Thus the quest and chaos plotlines emerged in the foreground as life with FMS became tolerable and changed in some way, or intolerable and out of control.

This study will propose that quest narratives told by the individuals in this study were characterised by telling two further plot-lines of either active engagement or active disengagement. This is a development of Frank's original quest narrative (1995) and demonstrates how participants with FMS were able to describe alternative ways of being that enabled them to 'successfully' with impact that FMS had on their lives and bodies. It challenges the concept of quest being a narrative whereby "the teller returns as one who is no longer ill but remains marked by illness" (Frank, 1995 p.118). The participants who enacted active disengagement actively sought medical labelling and identification as 'ill' or 'disabled'. They contrast with the 'heroes' that survive and overcome illness i.e. those who are actively engaging, and appear to actively resist any attempts to challenge their way of coping and living with their illness.

### **5.6.1 The need for change**

The theme a 'need for change' in this study was one of the main identifying features of the quest plot; life was forever changed and would never be the same. The dawning of this realisation could only come about once the participants knew what was wrong with them. This resulted in the opportunity for the quest narrative to become enacted once they had been diagnosed and there was much individual variation in the time this took. This was influenced by the time taken to be referred to someone who made the diagnosis, the time it took for individuals to consider something was wrong and seek help, and the time it took to interpret the significance of the diagnostic label.

Within this study it is proposed that two types of quest plot-lines emerged to characterise how individuals with FMS utilised their diagnosis and made sense of what living with FMS meant to them. Whilst there was heterogeneity within their stories, two common scenarios appeared to be enacted that were both linked to the inevitability of life never being the same again and the need for change to take place. Within the active re-engagement sub-plot participants, either independently or with outside help, enacted a narrative where they were able to return or recreate a life story that described how they were once more integrated within their home and society. This contrasted with those participants describing an active dis-engagement plot who described a narrative of living successfully with FMS that involved a conscious decision to withdraw further within the home and society. These participants rejected external efforts to engage with them, as this challenged the satisfactory status quo they had arrived at..

#### **5.6.1.1 Diagnosis as enabler**

The sub-theme 'diagnosis as enabler' was pivotal to the theme 'need for change' and symbolised the opportunity diagnosis gave for the narrative preference to be modified. Until diagnosis participants had been in either chaos or restitution and frequently alternating between the two. When they were uncertain of what was wrong with them, diagnostic tests were inconclusive and treatments failed the chaos plot line was in the



foreground. At other times restitution appeared to be the dominant story line; there were many times when they were hopeful still that a diagnosis would be found and cure prescribed. Whilst short term measures were taken and changes made to their lives these always remained firmly within the context of the modernist context of 'for every illness there is a remedy' (Frank, 1995). None of these changes were initially perceived as being required for anything other than the short term.

After living with the uncertainty of not knowing what was wrong with them the provision of a diagnostic label provided the opportunity for all three plot lines to be dominant to varying degrees. Knowing they had FMS swiftly returned some of the participants (as described in the last section) to chaos as they were faced with a condition that had an uncertain trajectory and no definitive treatment. In contrast a minority still believed resolution might be possible, and if not today then at some point in the future.

However the majority now began to migrate towards telling a story where quest was predominant.

This change in narrative preference seemed to occur once participants had taken the time to consider their diagnosis and what it meant to them. This in turn was mediated by the information available, combined with their unique beliefs and illness experiences. The acquisition of a diagnostic label provided them with access to information previously denied to them. This was either resourced from third parties e.g. the Rheumatology Consultant, or self resourced e.g. from books or the internet:

"How did you feel when you saw the Rheumatologist and he diagnosed you with fibromyalgia?" CJD

"Well I've got two friends at church who've got it and they've got the same symptoms. And it helps to talk to them about it, they can come up with ideas you know that can help it" Participant 7

“Did the doctor give you any information when you saw them?” CJD

“My own doctor gave me a leaflet, a paper off the computer to read for self help groups and things. It was saying what is fibromyalgia, what you can do about it. I know they can't cure it but it's what they can do to help it. And I'm going to Cedars, and they can teach me how to live with it” Participant 7

Together with the promise of treatment and benefits this initially guided the telling of the restitution plot line of “and tomorrow I'll be better”. However, on realising that a cure was going to remain elusive they either plunged into further chaos (as highlighted in the previous chapter) or moved into the telling of stories of quest.

At this point it appeared that all of the participants had interpreted FMS as a condition where ‘nobody knew the answers’. However, in contrast to the chaos narratives where participants told of how they had lost control of their body and symptoms these participants appeared to acknowledge that now they were certain, and able to begin to accept, the uncertainty they were faced with. They described how it was unlikely that there would be a cure and a return to normal from the perspective of how their bodies felt and behaved. As a consequence the lives they lived were likely to remain unpredictable and at odds with that which had been lived previously. Diagnosis now presented an opportunity for them to consider changes that would reconcile their previous expectations of themselves, their bodies and their lives with what was now a changed reality. This was demonstrated in the first interview with participant 16, who was off on long term sick leave from her job as a health care assistant:

“Did being diagnosed affect what you think about going back to work?” CJD

“Yes. I've realised that I probably can't go back. I want to, I really enjoy the work. But how can an employer cope with this? You don't know how things are going to be from one day to the next. I mean they can offer flexible working but only if you can give

them some idea of when you can work. They can't be changing it every day or every week just because of how you're feeling. You can't plan rotas and workloads like that. And now I never know how I'm going to be feeling. One day you think 'yes I could go back, I'm feeling okay' and the next day you're back to square one. And I've got to meet with them to look at what's going to happen next. But I guess I'll be finished on the grounds of ill health" Participant 16

Diagnosis and the ongoing experience of living with FMS seemed to lead these participants to consider two related issues. Firstly what lives did they envisage and could they accept living now that they had FMS; secondly how could they enact this new life i.e. what might they need to do or to happen to enable this to occur. From this position there then appeared to emerge two different aspirations or realisations: one was to attempt to re-engage with life whether as before or in a different guise, the other was to disengage.

Being diagnosed with FMS also appeared to provide their partners and family with the opportunity to support them in their quest narrative. There appeared to be a growing acknowledgement for all that if they were to adjust to life where FMS was present changes would need to take place within the home environment. Diagnosis not only facilitated the realisation of this but also by validating the illness experience provided the opportunity for this to take place. Participant 12 described how she had had a difficult relationship with her son for a long time. She felt he did not understand her inability to move about quickly especially first thing in the morning and this used to upset her. Following her diagnosis he was still impatient but came to help her and she no longer felt she put herself under the same pressure:

"I'm not dressed at that point. I've still got me gown on. And me sons going 'get dressed, get dressed mum' 'cos he gets here early you see, he's got his own house. And he's been building me a garage and then he's going to build some kennels from breeze blocks. And meanwhile he comes and lets all the dogs out, and you know they

run about or he feeds them, the rest of it. And he's going 'get dressed mum, get dressed mum. I want to go here'. Oh you know now I just sit there, wait till I feel better. I won't move"

For some participants diagnosis had enabled them to ask for help to perform tasks about the house. For others it meant their partners could ask for work to provide them with flexibility so they could provide input at home when it was most needed e.g. getting up in the morning.

The process of diagnosis was therefore symbolic in enabling participants and significant others to consider the condition they had and the potential impact on life present and future. From this point life was acknowledged as never being the same as before.

#### **5.6.1.2 Actively re-engaging with life**

This study proposes that the sub-theme 'actively re-engaging with life' was the most dominant plot-line occurring within the stories of quest told by the participants in this study; this was evidenced in the interviews with participants 1, 2, 4, 5, 6, 8, 9, 12, 14, 15, 16, 18, 19, 21. This plot-line showed some similarities with the memoir and automythology narratives described by Frank (1995). Their stories highlighted how with diagnosis came the acknowledgement that cure was unlikely to occur and this was reinforced over time as none of them achieved resolution of their symptoms. This group was then characterised by their ability to then consider how they were going to re-engage with life. This involved them understanding and implementing changes so that life could either be lived in a similar manner to before or differently.

Within the first interviews these participants were beginning the process of interpreting their diagnosis with FMS and absorbing the realisation that life was never going to be the same again. Diagnosis had provided them with the opportunity to decide how they were going to manage living with FMS. They appeared to be faced with two decisions:

to return to the lives that they had previously lived with modifications or to recreate new lives. This then required negotiation with themselves and their significant others (at work, home or with friends) so whichever course they chose could be enacted.

For the majority of participants within this narrative typology a new life, both present and future was considered and depicted. However on rare occasions they were able to describe an ability to live as before in some dimensions e.g. going out, or doing the housework. This usually coincided with their symptoms being well managed and other elements of their life going smoothly. Over the course of the study they described what they thought the future would look like in the short and long term and how this was then enacted was demonstrated in the descriptions they gave of what was happening in their lives.

For all the participants telling this plot active engagement was most noticeable in their attitude to work. Participants (1, 6, 9, 15, 16, 19, 21 ) had all managed to remain in employment after they became ill and in the period of time leading up to their diagnosis. They described how their bodies were able to cope with work and the impact that working whilst living with FMS had on them. They had made a decision to remain in these jobs as a result of modifications that they were either offered or asked for.

Participant 15 was typical of this group and throughout the study showed strong evidence of quest and restitution within her narrative. She had following diagnosis moved very quickly from chaos to restitution and then to a quest narrative. The majority of her interviews were spent describing the changes she had put in place to manage FMS and integrate it in to her life. Within the work environment she highlighted how she had the advantage of having insight into what support was available in the work place to help people with disabilities. She was very conscious of the 'advantage' that this gave her compared to others she encountered with the condition. An example of this was given when she described the support she had been instrumental in putting in place at work:

"I'm lucky. I know what I can get, at work. Because I've worked with disabilities I know what I'm entitled to. So this job, I've got a proper chair, and I don't have to do any lifting. And at home my husband gets carers allowance, because I can't get up in the morning and he does that and helps me get dressed. And I get mobility so that helps pay for taxis if I can't get the bus to work because I'm too bad one day. And part of me wants to tell everyone what they can get, and I feel bad, but I've not got the energy to do that. Maybe one day. It doesn't seem fair that I get it because I know what I can get and what to put on the forms. But I've got all on going to work"

The majority of participants however were not in work at the initial outset of the study. For some e.g. P4, 12, 18 this was because of lifestyle choices they had previously made. For the remainder that wanted to work they had been unable to remain there as a consequence of employers, or they themselves, questioning their ability to perform the necessary tasks. Participants 5 and 12, had managed to secure alternative employment by the end of the study, and highlighted how difficult this had been when they had a poor sickness record, and a condition with an ill defined management protocol. This then coupled with the ongoing unpredictable and invisible nature of the condition made them 'poor' candidates for work. However, they highlighted how they had attempted to overcome this by choosing jobs that weren't physically demanding combined with working part-time and where possible with flexible hours.

By the end of the study a couple of the other participants (P16, P18) who had not been able to return to work were now beginning to contemplate how they might do this. They described how they now felt they were at a point where they understood and were able to manage their symptoms much better. Whilst FMS remained unpredictable they considered themselves much better able to cope with it.

Consistent amongst all these participants was the notion of how going to work conferred both loss and advantage to them, which strongly influenced their desire to remain or return there. Going to work had an important role to play in the financial

affairs of their households and for this reason they considered it imperative that they remained there as long as possible. Without their income it would be likely that the lives of themselves and their families would have to undergo considerable change including the possibility that they would have to find somewhere else to live.

This is exemplified by Participant 9 who recently bereaved was now the sole provider to her three children. Changes in their lifestyle had already occurred due to the death of her husband and she was keen to retain the home they had shared to provide stability for her children. She was off sick from work at the time of the first interview, but had returned by the time of the second interview, and talked about her concerns about returning but also her need to return:

"You know you have to start moving a bit, start dealing with it, start trying to get your own life organised. You know in time you will get on with it but my worry is will it aggravate it? If I'm going back to work and to start typing again I know I'll start getting pains again. And without typing I can't work 'cos that's my job, letter writing. I can't sit on a telephone all day because we don't have customer services anymore, it's all relating to your computer work. I've got to get on with my life, get back to work, start to do my normal routine. Obviously I will need the money soon because you know sick pay only pays you for so long. And it's just me now to pay the mortgage. I'll have to get back to work. It's not fair on the kids, they've lost their dad. So I need to get back to pay the bills, keep things normal for them"

Going to work was not just motivated by financial gain. For these participants' it was also linked with their self perception and well-being. They all described how before FMS they had enjoyed going to work and how it had provided them with a purpose. For participant 6 this was especially significant as he strongly identified with the role of provider within his household. He had been very concerned when his symptoms first began of his inability to fulfil his obligations of husband. Remaining in work was pivotal to him describing himself as "being useful" when he did so.

Work also provided a welcome opportunity for socialisation and this once more was especially important to P9 who was now increasingly restricted in her opportunities to socialise now that she was on her own. Work provided the chance to interact and 'have a laugh' with others and was necessary for their 'sanity'. Being amongst people that they knew, rather than in a new work environment was a key part of this and something they were keen to retain. Participant 6 recalled how being in work as a butcher, in a job he had done for many years, had provided him with the opportunity to 'be himself' and interact with customers he had known for a long time. In fact at times he could forget that he was ill:

"I can't do any other work; who'd take me on? I'd try another job but I can't fit in. Sitting on a till putting things through that would drive me insane. Going to work is a goal. I've got to get out. You see I was brought up the old way, you're never late for work, you've always got to get to work, you die at work and that's helped me a lot. I can go to the butchers and I'll say 'good morning madam you're looking as lovely as ever. Where are you going, anywhere exciting?' I'm P6, keep a smile on your face. But the real P6 is at home not at work. But while I'm there sometimes I can forget"

The symptoms of FMS meant that the struggle to cope with the physical demands of their jobs never abated in spite of some of them taking on more sedentary roles. They described how in an 'ideal world' they would be able to work as and when their body allowed, so that on a good day they could do more. They had also learnt either through attendance on the PMP, self-resourcing information and trial and error of the benefit of pacing. As a result they considered that they could remain in the same jobs by negotiating with their employers, flexible or reduced working hours. Participants 9 and 6 reduced their hours in order that they could cope with the physical demands of work in contrast to Participants 1 and 15 who not only did this but also negotiated the option to work them flexibly.

Alongside employers facilitating the ability to remain in work this was also supported by changes within the family. Going to work and the effect it had on their well being



inevitably led to them feeling tired when they got back. Doing household chores on the days they had been to work was either very difficult or impossible. Negotiation was further performed with those at home to ensure a level of understanding that meant on the days they had been working, little else physically or mentally demanding was asked of them. Those days pre-FMS, when they had been able to go to work, do the housework and go out were over.

For participants 1 and 6 this meant a greater reliance on their partners to help with chores, even though the partners had the same levels of commitment as before. For participants 9 and 15 it meant a growing reliance on their children to help. Participant 9 felt that being at Secondary School they should be helping her increasingly around the house but constantly felt guilty that they did not have a choice in this. She was concerned that the passing of their father had required them to grow up more quickly, and now FMS was adding to this:

"... You know today I wanted to put the washing out and I can't because it's too strenuous. I just feel like never moving my arms and some of the clothing obviously is heavy. You know it's an effort and it's a strain to put things out or do anything, everyday housework" Participant 9

"So how do you manage that? Obviously you've still got to do some things like washing" CJD

"Well my daughters help me a lot. My daughters 'cos they're seventeen and thirteen so they do help me a lot. I mean I do rely on my kids a lot and I think it's unfair on them 'cos they're obviously undergoing grieving. And my son he's nineteen at Uni. He's usually at home but this week he's away 'cos he's got exams. He does all the grass you know cutting and the heavier things. I mean there's been urges to take the spade and do the gardening because it really does need doing. But you know, my whole body is just restricting me getting up and doing it" Participant 9

Alongside work the participants had additional commitments and roles at home. These commonly included doing the housework, shopping, doing DIY, gardening and organising family schedules. When FMS had first begun they had continued to do this but as time passed were increasingly unable to do so. In the initial interviews the participants had either withdrawn from their responsibilities or continued to do so without consideration of how best to go about it. They were frustrated by this and once they had been diagnosed they were able to consider the chronic nature of the condition and how if they wished to resume a role in the house they would need to consider how to do so.

The majority of them remained unable to do the heavy tasks in the house e.g. moving furniture to clean, but were able to negotiate with the family what they could do. In this way they began to feel of value and acknowledged that this combined with the physical activity made them feel better most of the time. They described how they still had bad days and had to learn to accept these. At first this was an inconvenience as they were poor at determining what they could realistically achieve but over time they became better at understanding what they were capable of, on both a good and bad day. They told of how previously they might have been fastidious about ensuring their commitments were met e.g. their housework, they had over time learnt to adjust to the fact that some days they weren't able to do as much and 'this was okay'.

Participant 18 described in her third interview how she had adjusted to this:

"You were talking about the table (*having a cup mark on it*) and the housework, and being house proud. How do you manage the housework these days?" CJD

"I've had to become more laid back, either that or commit suicide. I would have been literally out of control. So I had to alter my ways. I only Hoover twice a week now, I used to do it every day. I take it as it comes and he's brilliant" Participant 18

"What has been the difference?" CJD

"He's helping more. He's done things, not the way I would have done it but it's done I suppose. I suppose I've changed. It's made him do more because at one time he was idle. I think its old fashioned where she would do the housework and he would bring the money in and I think it's made him more modern now. I still do all the cooking and things" Participant 18

In a similar way this group placed great emphasis on either regaining their past or renegotiating new, social lives. They were keen to highlight that previously they hadn't gone out a lot but when they were first ill with FMS they initially felt obliged to withdraw from socialising. This was what was expected from ill people and was what they expected from themselves if they were to recover. As time passed and they received their diagnosis they understood the importance of re-engaging with all aspects of their life. Socialising was important in raising their mood and in gaining support from those people around them. By the second and third interviews they were able to give examples of how they were learning to manage this once more.

They all appeared to describe how they had become more discerning about whom they socialised with and how they did it. Whereas before they might have gone out, now they stayed at home. Previously they might have had lots of friends now they had fewer and had learnt to recognise those that showed them empathy and support and were helping them to cope. Similarly they recognised those that 'drained' them and who seemed to make them feel worse after they'd been in their company.

Whoever they chose to engage with they consistently identified that adjustments had to be made for any socialising to be done and this was not restricted to physical constraints. Where previously they might have gone out to a restaurant both finances and their physical condition now made this more difficult. Social contact was maintained instead by them visiting their friends and family or having them over. They explained the nature of the condition and an understanding was communicated that they might need to move about if they became uncomfortable or to rest if they were tired.

Participant 6 described in interview 1 how he particularly enjoyed having his grandchildren over but he had had to adapt what he did with them. Where he might have previously got on the floor to play with them, now they were encouraged to come to him and play games that he was physically able to do. Over time they had learnt what he couldn't do and to allow him time to rest when he needed to:

"And the grandchildren. Last time you talked about how you played with them, how you'd had to adapt and can only play with them for a certain length of time. How are things with them now?" CJD

"Jacks full on now and the other one he's in Australia. We have to restrain Jack a bit now and he's had to learn to adapt a bit and let me go for a sleep. He used to go to bed with me but not now. But he'll come and wake me up and then we'll go down and play in the workshop with the hammer, nails and screws. And we'll go out on the scooter and he'll sit on my lap with my legs over there (*points to the left*). And he drives it, well when there's nobody about and we go down wiggly roads and chase mummy and gran" Participant 6

Being diagnosed enabled them to explain to their family and friends what was wrong with them, how it made them feel and what the future was likely to look like. They had been surprised that some of their friends and family seemed to struggle with this, in particular the notion that there was no treatment or cure. This continued to feel like there a lack of credibility was afforded to them: whilst they had met the expectation of others to be diagnosed they were still failing to meet the modernist requirement to be cured. They therefore chose to no longer engage with these people.

In contrast the partners and families of some participants seemed more open to the notion that FMS was a chronic condition that whilst not curable was manageable. They appeared to visualise a role for themselves in assisting the participants to realise this. They sought further information and answers from them and offered potential

solutions to how they could continue to do things together. Participant 16 described this when asked about how her husband helped her:

"He (*her husband*) comes everywhere with me. Every hospital appointment, to the doctors. We're in it together. But it's the same for him (*her husband*). He's got prostate cancer and I go with him. We both support each other. He has to do more to help me physically, but that's partly him. He won't let me get out of the bath by myself and he does the physical work in the house. Sometimes I can stand to cook a meal, but he'll help me prepare it. He didn't do anything like this when he was married before but he wants to and I've had to learn to let him"

These participants tried to demonstrate how they had managed to retain or restore other domains of their lives. Holidays were something many had enjoyed prior to the onset of their illness. Initially they had withheld from these as they sought to discover what was wrong and hoped that once better they would recommence them once more. With the realisation that they were not going to get any better they began to consider how they could do this again. Once more changes had to be made by all concerned to either do that which they had previously done, or to look at amenable alternatives.

There was an appreciation that they were unable to cope with travelling distances in the same way, independent of what mode of transport they used. Sitting still was uncomfortable and they needed to take regular breaks to change position and more about. Similarly they recalled how when they did travel they would be much more tired than normal the following day, and thus itineraries had to be planned accordingly. Within the second and third interviews examples were offered of how they had managed to enact this with variable degrees of success. Participant 5, in her second interview, described how she and her husband had been away for a long weekend together. They had been both excited and reluctant about doing this and she told of

how they had planned this together and then worked together to manage the holiday once they were there:

"We decided to try going away for a few days on our own, without the children. To give us both a break and to see how it worked out. We went to Prague; not too far and somewhere we both wanted to go. He (*her husband*) had to carry the bags and I had to get up and move about, at the airport and on the plane. And when we were there we did something one day and rested more the next day. I mean he's (*her husband*) great; he knows if I can't do something and will make me take things easy"

All of them acknowledged that this was a continual learning process that required action, reflection and readjustment. None of them regretted trying things even when they had not gone to plan. This was considered part of learning to live with this unpredictable condition and they were gradually becoming used to, if not always coming to terms with, this. Changes were absorbed in to their lives and became acknowledged as prerequisites if they were to continue to engage.

The previous examples of this sub-theme have placed an emphasis on how life was being lived during the course of the study. Discussion also took place of how the future was going to be. For these participants there was no immediate change in how they saw the future and as they saw it, 'it was back on track'. For participant 9 this meant that her future was one where she would continue to work until her children had grown up and left home, at which point if they were financially independent she might be able to finish or reduce her hours at work to make life easier. This is highlighted in her second interview and was no different to that envisaged before she was ill:

"So how do you see the future?" CJD

"Well you hope that you'll get better but for now I imagine I'll carry on working until the children have left home, been to university, whatever they want to do. It's no different

now. It would have been different if my husband was alive. You talk about the things you want to do together when you retire. That's not going to happen now. That changed my future, not this" Participant 9

For participant 1 she considered a future where she gave up her current employment and became self-employed. Whilst the onset of FMS had made her consider doing this sooner than she had previously anticipated, it was something which she and her partner had always spoken of. And for participant 6 he looked forward to eventually retiring and being able to enjoy still getting out into the country and going on foreign holidays. There appeared no reason why FMS should stop their planned life stories from materialising.

It was apparent throughout the study that it was not just their lives that had changed. For this active re-engagement to be enacted others around them had to be involved; they needed to both understand and accept how life and its daily events were now to be managed. They also had to have a shared vision of how the future could be. The participants described supportive and understanding relationships with work, family and friends and acknowledged that without this the reality of living with FMS would be very different. This demonstrated once more how FMS did not appear to affect one life but had wide reaching effects on others around them. This was in part linked directly to the symptoms they had and the impact they had on others. It was also linked to the adjustments others were prepared and needed to make if the participants were to re-engage with life.

#### **5.6.1.3 Actively disengaging with life**

This study proposes that the sub-plot of 'actively disengaging with life' was the least common type of quest story told by participants within this study. As with those that showed a preference for re-engaging, these participants (7, 11) had considered their diagnosis and what it meant to them. They showed evidence within their stories of how they envisaged their lives being both now and in the future. In contrast to those

that showed a predilection for active re-engagement these participants, in their first interviews, were already demonstrating how they were enacting their lives in a different manner. This was typified throughout the study by a continued and further withdrawal from family life and responsibilities as well as societal obligations. This plot-line shows some allegiance with quest as described by Frank (1995) as life is forever changed. However the descriptions of how this narrative was enacted by participants appears to be at odds with what societal expectations demand of individuals successfully managing chronic illness.

These individuals described how diagnosis for them had meant that they were now unable to visualise a future where life would ever be the same again. This temporarily plunged them in to telling a chaotic plot but this was short-lived as they began to reconcile themselves with what life could now potentially look like. Previously, they might have struggled to get help from family, friends and external agencies but diagnosis appeared to legitimise both the asking and receipt of help. Whilst before they had felt obliged to try and enact a restitution narrative and get better now they seemed to feel as though they had been given permission to withdraw from their obligations. It was as though they had verification that they were ill and with this came certain dispensations. Unlike those participants in chaos they didn't reject or 'fight against' this change in their lives but accepted it and further seemed to seek out opportunities that would further facilitate this process and way of being.

Participants 2, 8, 11, 14, 17, 19 had been working prior to the onset of symptoms but were now unable to see how they could return. They appeared to either have employers that were not willing or able to accommodate any changes to their working practices or had not considered alternative ways of working. When they had first been ill they had gone sick from work and had envisaged an eventual return. With diagnosis they adopted the stance that this would not be possible and finished work.



Disengagement with employment was also evident in some participants who hadn't been in work prior to the onset of symptoms. When asked if they ever saw themselves being able to work they were emphatic that this would not be possible given the symptoms that they had. They were unable to see how they would be able to find suitable employment that would be able to incorporate both the symptoms they had but most importantly their unpredictable nature.

Within the initial interviews the stories they told placed emphasis on not wanting to wait to explore the potential effects of treatment. Instead they expressed a preference for looking at what support was available to them from external sources, most commonly invalidity benefit and disability living allowance. There seemed to be a perception that they had 'earned' this right to withdraw given the years of work they had previously done or the condition they had. When external agencies seemingly pressurised them in returning to work they felt unsupported and that they did not understand the difficulties this presented. Participant 11 typifies this in her initial interview when describing how the 'Yes to Work Agency were in pursuit of her:

"I mean she's made this appointment for me (*held up Yes to Work Leaflet*) at the Department of Work and Pensions in Long Eaton for 3 o'clock tomorrow afternoon. If I'm really bad I'll have to phone her up and say 'if you want to see me you'll have to come here because I'm not up to it'. And they don't understand that you can't plan that far ahead because you don't know what you're going to feel like on a particular day. And that's the problem with work, they don't understand what you're saying. They just think you don't want to come. But I'm saying 'yeah I'd love to come back to work, just tell me how?'"

Over the course of the study the return to any form of employment became increasingly distanced from the vision that they had of their future.

As well as withdrawing from work obligations there were also examples of how they increasingly withdrew from obligations at home. The participants' representative of this typology often lived alone and therefore the extent to which they were able to enact this was variable. However for all it was the outcome that was desired. Where it was feasible it was typically in domains of housework and physical activities that they attempted to disengage. They described how previously they had liked to keep their homes clean and tidy; now they were able to accept that this was not a priority and that they should be excused for this. Given the condition that they had and the restrictions it placed upon them it was acceptable for them to live in this way either not performing these tasks or becoming reliant on others to do them for them.

In this process of disengagement they then tried to utilise other means to get these tasks done. This could either be by asking friends and family to help them, or by accessing benefits that might be used to pay for e.g. a cleaner. If either claim was rejected they explained how they felt disenchanting with society; their perception was that they were relinquishing these duties in order to help them manage their condition yet society was failing to meet their expectations:

"I was getting the disability benefit the middle rate. I see myself as disabled now but I had to have another assessment. And I must have been having a good day when I filled the form in because what they did was drop the rate from the middle rate to the lower rate. And now that's caused huge problems for me. I mean that was there to help. It paid for taxis, a cleaner, someone to do the decorating. I can't go to work and why should I. I worked for years and now I can't, and those that have never worked they get it. I'm going to appeal"

Participant 11

These participants also detached themselves from social obligations with friends and family. They seemingly became content to stay at home and become increasingly socially isolated. This was something that appeared to be make them feel sad, as evidenced in the change in tone of their voice when talking, but they were apparently

accepting of their circumstances the majority of the time. Living with FMS meant they no longer had the energy, physical ability or financial means to go out as previously. This is highlighted in interview 3 with participant 7:

"You mentioned that you don't get out anymore or see anyone. Can you tell me more about that?" CJD

"Well at first people come round, friends, family. But then when you don't get better some will still come. But others they're not interested. You can't do anything and they don't think you're much fun. You're the same person, but they don't see it that way. You can't do the same things, you don't always feel like talking. So they stop coming and you don't go out because you can't or you don't feel like it. And it's just easier to stop at home. I'm comfortable here, got everything I need. I mean I do get fed up but I'm okay. I can do what I want here, and if people want to come and see me, okay"

Additionally the number of friends and family who came to visit them, reduced over time. At times this returned them to chaos as they recalled a life that had previously looked very different, and considered the people who no longer called them. However, they appeared to concede that this was their lot and they could understand why people had reacted in the way that they had and disengaged with them.

What seemed to distinguish this group from those who were telling chaotic stories was that people did still sometimes come to see them. Those that came appeared to play a significant role in their lives and interacted with them in a manner that they felt conferred compassion and credibility. Sometimes they would suggest ways in which they could withdraw further suggesting aids and adaptations that might help, or benefits that they might access. They would sympathise when people that did not know them as well seemingly questioned them and their inability to function at their previous level.

Those participants that showed a preference for disengagement also seemed to show evidence of increasing withdrawal or non-compliance with conventional treatments other than medication. They continued to attend their GP on a regular basis but appeared increasingly reluctant to try additional treatments that were suggested. Medication use was complied with but any suggestions to exercise or attend physiotherapy were rejected. Arguments were presented on why they could not comply with such treatments given the symptoms they experienced. The reasons they gave typically included being unable to get out and use transport to access these treatment/management options; having a lack of finances to take up e.g. swimming; or being unable to consider them given the physical condition they were in i.e. they were too tired or in too much pain. This is typified by participant 11 in interview 3:

"You said that you'd been offered some physiotherapy but you didn't go?" CJD

"What could they sort of physically do? I mean how can I exercise with this pain? It's like those Yes to Work people. They don't seem to understand that you might make an appointment but you don't know if you can go till the day, you don't know how you'll be feeling. And then if you don't go they get shirty"

These participants emphasised that they continued to present to health care to ensure they were not being denied any remedy that would provide them with the elusive cure. This 'remedy' was however only going to be palatable if it was externally derived i.e. taking a medication or having treatment 'done' to them, as opposed to internally derived i.e. involving them actively engaging as in exercise.

### **5.6.2 Living an acceptable life**

The theme 'living an acceptable life' was present in the stories of all those participants telling stories consistent with the quest narrative. The characteristic feature of quest i.e. 'life will never be the same again' was reconciled by these participants; this was independent of whether they actively engaged or disengaged and they all

demonstrated features consistent with an acceptance of their life as it was now. This in turn was influenced by the sub-themes of 'acceptance of contingency' and 'still being myself'.

#### **5.6.2.1 Acceptance of contingency**

Acceptance of contingency appeared to be a defining feature of the participants telling stories symbolic of quest and was strongly associated with the ability to live an acceptable life. However doing so meant responding to the 'loss of ordinariness' of their bodies and the lives they previously had. Initially the desire and past knowledge of restitution had presented and was manifest in the expectation of their bodies to act in certain ways and respond in accordance with medication taken and treatment given. When this had failed and the realisation that it was unlikely dawned, chaos was enacted. The ability to move into quest then seemed to be aligned with the ability to renegotiate what an ordinary body and ordinary life meant to them. From their interviews it emerged that they had conceded the loss of control over their bodies and come to acknowledge what was now predictable was the unpredictable nature of their bodies. This realisation seemed to confer control once more over their life and they put in place strategies to try and minimise a descent into chaos. They often still searched for reasons for the unpredictable nature of their illness but grew accepting of the fact that whilst sometimes this was possible more often it was not. This is typified by participant 16 who in her second interview described the changing presence of the pain:

"The pain still varies from day to day and it seems to be a different part from day to day. At the moment I seem to have a niggly problem with my lower back and my knees have been very painful as have the ankles but I just think I learn to get on with things even though I'm always in pain. I'm never not in pain, but I tend not to worry about it"

That the pain was no longer a threat or something to be concerned about was typical of those participants in quest. There was a growing sense over time that for them the symptoms, including pain, became a 'familiar intruder' into their bodies and lives.

Over the course of the second and third interviews the participants appeared to come to terms with the limitations of their bodies. New routines were developed to manage work, social and home lives. These took into account what they were able to do and most of the time they stuck to this. This unpredictable body now rarely behaved in a new or unexpected manner and as a result they became accustomed to this new unpredictable way of being. They were able to reconcile the symptoms and the effects they had on their lives and this demonstrated the acceptance of contingency. Over time there were far fewer examples where their body was considered as a separate entity and the body and self seemingly became one.

What further seemed to enable this change to take place was (a) the belief that whilst the symptoms of FMS were unpredictable how they chose to live with them was a matter of choice and (b) the ability to balance these symptoms with living satisfactory lives. What constituted a satisfactory life varied for each individual but it seemed that there were two common themes that permeated this. As described in the previous two sections there were those that attempted to actively re-engage with life. They would do this in two ways: they would attempt to live their former life with modifications or reject their former life and recreate a new life story. This was in contrast to those that withdrew from obligations and actively disengaged from their former lives.

What in part determined the way in which they managed contingency was an association between the story being told, satisfaction with their previous life story, their satisfaction with a potential new life, and the support they had available. Participant 1 described in her third interview how she and her partner had considered the potential they now had to work for themselves:

"It had been something we'd always talked about, one day working for ourselves. Now it's something we talk about all the time. Is there something that we could do, that would make life easier and make life better. We've got used to living off less money, with me reducing my hours. And we've been thinking about what we could do you know that might be more manageable. Better for both of us. This makes you think about things"

The ability to remain in quest and accept their unpredictable bodies' and lives was not static. They told of how they could often cope with one symptom at a time or with multiple symptoms when they were not too intense. However, when everything exacerbated and there appeared to be nothing they could do to manage them, it sometimes became too much and this was when they were at risk of returning to chaos.

#### **5.6.2.2 Understanding what helps**

An important sub-theme of living an acceptable life was 'understanding what helps'. Once a realisation had been reached that life was never going to be the same again, the majority of participants whose narratives were consistent with quest appeared to face the effects of FMS 'head on'. They told of how they attempted to engage with strategies that they had either learnt themselves or adopted from others.

A number of these participants had attended the pain management programme and heard quest stories from other patients attending the group, or those that were brought in to specifically talk to them. Similar stories were heard at the FMS support group but those that had attended continued to feel that there was a greater demand for restitution to be heard there. Hence within that forum there was an emphasis on new 'wonder' treatments. In contrast the PMP offered realistic solutions and they were able to visualise what the future could look like. They gained hope from hearing of what was possible if they could adopt the tactics they had heard described:

"My GP first gave me the leaflet about the support group. She said 'go to the support group and listen to other people but don't start buying all these tablets that are on the market'. So then I was curious and I went there and have been 5 or 6 times. But the speakers are often trying to tell you about some 'miracle' something they to want to sell. And lots of the members they're just full of negativity, they all seem to want a good old moan" Participant 15

"What about the pain management group?" CJD

"The Cedars that was better. The pain management programme had people that came and told you about what had helped them, and they didn't talk about miracles, or get you to buy something. This was just people like you who were getting on with things, getting their lives back" Participant 15

Great value was placed on the ability to talk with others in a similar situation and they overwhelmingly felt it was the interaction with the other patients rather than the health care practitioners from whom they had gained the most benefit. The other participants understood what they were going through and could offer both first hand advice and empathy.

Both those participants that were actively engaging or disengaging embraced what they had learnt. The advice they gave was often adopted from both the health care professionals and the other patients. Those that were actively re-engaging told predominantly of how they had learnt to pace, exercise and manage the pain and fatigue when they became intolerable. This was in contrast to those that were actively disengaging who appeared to have gained most from the advice on benefits and the importance of rest.

Both groups of participants were increasingly aware throughout the study of what aids and adaptations were available to help them. In the initial interviews there had been



some discussion of finding out what might be available or more information about what they knew to be there. However, at this point they generally considered that there use would signify the longevity of their condition and they didn't want to acquire things that wouldn't be needed in the long term. In addition there use was also associated with being disabled or ageing and they rejected this notion.

By the second and third interviews a transition had taken place. Many had acquired tools to help them and these ranged from long handled pick up sticks, to devices to help in the kitchen e.g. electric can opener, to mobility aids e.g. electric scooters, wheelchairs and walking sticks. Once more there appeared to be a distinction in how these devices were utilised. Some of the participants used them to further withdraw from activities i.e. to absolve them of the responsibility to walk any distance.

Participant 5 had procured a wheelchair which she used to go out with her family. They all enjoyed going out walking and with young children she described how she particularly enjoyed going to her local park. She had been struggling to do this and frequently found that family trips out were curtailed when she was unable to manage the walking that was required. Initially she had taken many rests but this impacted on how far they could go and was not practical on days when it was especially cold. Attaining a wheelchair meant that they could now go out and cover the same distances as before. She was conscious of how easy it would be to become reliant on it, so whilst she would sit in it she would also use it as a support to lean on and push as she walked:

"It took me a long time to get a wheelchair. But I've got a friend who's got spina bifida and she talked me into it. Made me realise that I was stopping myself from doing things and the kids. Being stubborn, not wanting to give in. So we got one and I don't use it all the time. Just if we're going to go out any distance, and it's like you're getting your life back, and the kids are getting their mum back"

They also learnt the importance of taking their medication and no longer considered the medication they took (predominantly selective serotonin re-uptake inhibitors and anti-depressants) attempts to psychologise their symptoms. They did however grow increasingly aware of the role that stress had on their symptoms. It was highlighted that this couldn't be abolished from their lives. Instead they tried to work with others to minimise it.

For some participants this provided their justification for withdrawing from previous obligations e.g. work. In contrast others tried to ensure that communication was embedded in their relationships to ensure problems never arose that could not be dealt with early on. At times stress was inevitable, could not be avoided and a normal consequence of life. However, they grew to understand the impact on their bodies and the consequences for their day to day functioning. They became aware of the need to make adjustments accordingly and highlighted how these adjustments had an impact on others. Participant 21 in her third interview described how she and her husband had moved to live with her father-in-law to help look after him. He had since died and they were selling the house: with participant 21 not working they were unable to afford to live there. Previously they would have managed the house move themselves but now they needed to bring in outside help at additional expense:

"When we moved house before we did it on our own. Packed and moved everything. Now we're getting help with everything. We're packing some of the things up that we can but I still have days when I'm good and bad. And he (*her husband*) is already doing extra shifts at work to make ends meet and then helping at home. It's just too much to do this as well. It's pushing us, the cost. But we've got no choice"

Understanding what helped was characterised as a process of trial and error which required constant revisiting. This was less apparent for those that had withdrawn from their obligations and more noticeable for those that returning to previous or new work

and obligations. This continued to challenge them but they seemed to accept that this was and would continue to be required from them.

#### **5.6.2.3 The desire for quest stories**

The theme 'living an acceptable life' with FMS was associated with the continued desire to hear and tell both restitution and quest stories. Restitution would always be the preferred outcome but those participants exhibiting a tendency for telling quest narratives also demonstrated an ongoing aspiration for them. Often when they were interviewed they would ask 'how other people managed?', 'how other people coped?' and 'were other people like them?'. This seemed to be two-fold: they wanted reassurance that 'things would be okay' and also 'that there were not alone' in their predicament. This was therefore once more evidenced in stories of both active re-engagement and disengagement.

This was further highlighted when those that had attended the PMP or FMS support group recalled the interaction with those they considered to be 'successfully' living with FMS. Courage and hope in particular was gained from listening to the patient experts brought in to talk to the group. Here were success stories of how to live with this illness by individuals who had experiences similar to them. Practical advice was gained which they tried to utilise if relevant to their circumstances. But, they also described the benefit in hearing of the difficulties other people had and how this had made them feel, Comfort seemed to come from the knowledge that they weren't alone.

This quest narrative and the desire to hear and tell such stories was exemplified by participant 16. She had attended the PMP and found much benefit from the strategies described and the support gained. Her apparent 'success' in completing this programme resulted in an invitation to speak to a future group. She had relinquished her job as a therapy assistant in the NHS and embraced a new life; she had taken

early retirement and re-married in an attempt to restore balance to her life. It was no longer the life she had envisaged but it was one she was content for now to enact:

"I was flattered when they asked me if I'd go back and talk to the next pain management programme. They thought I'd taken things on and would talk in the group. I'd got some experience from my job as an OT assistant so I guess that might have helped, and you're used to talking to people. And one thing we did touch on was how it affects your physical relationships. You know when I went to the group we touched on it but it was 'oh taboo' and we all had a laugh about it. But it's quite an issue and when I went to talk I spoke about it and it clearly was a problem. But I feel very lucky with (*her husband*) because he doesn't pressurise me. You know you don't think at this stage that life will be like this, but we're close and we touch and he is very understanding"

Many of the participants in quest also highlighted the benefit that they got from sharing their own and listening to others experiences. The majority of participants who had entered the PMP described how they had kept in contact with other patients who had attended. They highlighted the importance of supporting each other; there was particular merit in sharing with others who had first hand experience of what they were going through. They gained continued benefit from communicating with others; sharing new strategies that they had found beneficial and gaining hope listening to others who were apparently managing to live acceptable lives. This was consistent within both sub-groups of participants within the quest narrative. However, those who were actively re-engaging demonstrated a preference to meet in person, whilst those disengaging preferred to maintain contact using the internet or phone.

For those actively re-engaging the desire to hear quest stories was also evident within the other support networks that these participants had i.e. family and friends. They highlighted the role that sharing their experiences with significant others had and how these people appeared keen to share their experiences with them. Over the course of

the study they began to tell of the feeling of achievement they got when people told them how well they were doing. This was often not a one way process and a reflection of their relationships: they would both share their stories but they never felt as though they were being a burden as the focus of theirs was still often on their illness.

"I've told you about this friend I've got with spina bifida and we chivvy each other along. I can go out now for something to eat sometimes and we moan and take the mickey out of each other. But it's to support each other. When we're feeling rubbish we can pick each other up, and she'll tell me how well I'm doing. That I've got to look back at how I was 1, 2 years ago and I know she's right" Participant 5

The desire to hear their stories was rarely evident for the active disengagement group. Over the course of the study they described fewer opportunities to engage with other people and that when they did, few people wanted to listen to how they were unless they were in a similar predicament themselves.

#### **5.6.2.4 A considered self**

Typical of the narrative typology of quest is the belief that 'life will never be the same again'. As participants were diagnosed with and lived with FMS it became apparent of the consideration they gave to their identity. Initially all participants had wanted to enact the restitution narrative and be diagnosed and identified with an illness that had a known cause, remedy and cure. The initial interviews highlighted the dissatisfaction that was encountered when they realised this was not to be. Chaos ensued and the feelings of stigma and lack of credibility arose. However, even at this early stage there were two participants (1, 15) who were demonstrating the potential to move back into either restitution or now begin to tell a story more aligned with quest. They were keen to emphasise that whilst they might be presenting with the symptoms of FMS and unable to participate in life the same way, they were the same person. Participant 1 highlighted this in her desire to distance herself from her diagnosis and the ramifications this might have:

"So the term fibromyalgia, what does that actually mean to you? Because you described the fact that it's sort of a double-edged sword almost" CJD

"Well it's nice to know what it is, it's nice to know what you've got wrong with you but at the same time people think it's all you are almost. And it's obvious this is all new to me but, I just think in six months time I'm going to be quite bored with the whole thing. It's nice to have something definite to tell people, that's the main thing. But my illness is not what I am. It's not the only thing in t my life, there are other things"

For all of the participants in this study who predominantly told a quest narrative the initial diagnosis of FMS had conferred benefits. However once these initial benefits had been realised there appeared to be two discrete ways in which the identity of FMS participants manifested them selves. In the minority were those that wanted to embrace the label of FMS and become 'patients with FMS'. This contrasted with those that wanted the identity of FMS to remain in the background and to be replaced by either a new identity or their old one.

For participants 11 and 7 it appeared that they had relinquished many facets of their previous life e.g. work, social life and in doing so disengaged from the expectations of life. Having FMS appeared to give them permission to become a credible patient and be exempted from their previous responsibilities. They didn't appear to demonstrate any particular difficulties in being identified as 'long term sick' or 'disabled' and often seemed to embrace it. They also appeared unconcerned with how others perceived them. Being labelled had legitimised their condition and as time passed they continued to feel absolved of the need to justify their chosen life path. Participant 11 was asked in her second interview to consider how she now saw herself after giving up work and being in receipt of benefits and typified this sub-grouping of participants:

"Well its like I've said, I've always worked. As a nurse, the nursing home. And it's only now that I've stopped. What can you expect? I mean I try and do what I can, I live on my own. But with this what can you do? I don't want to be like this but those work people they are always trying to get you. I'd love to work for myself, but they won't help you with that. I could do what I wanted then. But no you've got to work for someone else. Well I can't"

Many of the participants who were actively engaging, once they had accessed support, treatment or information they then appeared to seek to distance themselves from the condition. They were very keen to portray themselves as the same people either living the same life, albeit with some modifications or adopting a new life to accommodate their condition. What often appeared to be central to their principal identity was the self, the person within the body.

This group of participants were frequently concerned that others might consider them in a negative way because of their illness. They were often concerned they would be thought of as 'lazy' as they made less of a contribution at home or at work. For them the ability to remain in a quest narrative involved the ability to confront this and is highlighted by P6, the only male participant in the study, who had reduced his hours of work from the first to the second interview and eventually retired as he was no longer able to manage the physical nature of his job as a butcher:

"Now I've found myself thinking about the past, a lot of times and I think to myself you're not supposed to think of the past, bugger the past. You've got to think of the future; what you want to do not what you have been doing. Comparing what I did do and what I can do now and this is a big thing in my mind at the moment, I feel useless. I've got to forget what I used to do and consider what I can do"

The impact that FMS had on their relationships was an issue discussed by some of the participants. When symptoms had first begun it did not appear that there were any

concerns of how having FMS impacted on their identity within this context. Withdrawal from sexual and physical intimacy was initially considered a normal response to being ill. Once they had been diagnosed there was a concern that the effects of FMS could impact on their own self perceptions within their relationships as well as on the perceptions of others. Being touched was frequently a painful experience and fatigue often made them feel like they didn't want to participate in sexual relationships. However, they also did not want to envisage a future where this aspect of their life was over. Doing so had the potential they believed for them to be perceived as unattractive, frigid and old and is described by participant 21 in her third interview:

"I really feel for him (*her husband*). We'd not been together long before this happened. And you know we've not been married long. We're not young things but never the less this isn't what you imagined. It's not that I don't want to be touched but you worry about whether he's going to touch you where it hurts, and because it moves about he never knows where to touch you".

None of the participants that had shown a preference for the actively disengaging narrative were in sexual relationships at the time of the study. For those actively engaging and in relationships there was evidence of how they attempted to maintain the status quo of life as it had been before albeit with some adjustments. Examples of how they coped included the development of cues for their partners that indicated their ability to engage or negotiating alternative positions that were less pain provoking. On occasions they would describe how their desire to be as before dominated and they would participate in sexual activities knowing that they might have to accept the increased pain this could provoke.

More commonly participants described how they had learnt to incorporate new ways of experiencing intimacy with each other. They told of how previously they had enjoyed active and very spontaneous sexual relationships. With FMS this was rarely possible and as they had learnt to pace other aspects of their life so they learnt to



apply the same principles to this domain. Often they would do this by putting aside time each week to be together. This was considered to be an essential part of their lives if they were to retain some part of their previous identity as sexual beings.

Participant 5 had described early on in the study the loss that she had felt when she was initially struggling to cope with the symptoms of FMS and especially the impact on her sexual relationship with her husband. Typical of this group of participants she recalled how they had learnt to communicate about what they could enjoy and a greater emphasis was placed on simply being touched. This provided an opportunity to explain how her body was feeling and this was then utilised to avoid either touching areas that hurt or touching them in a manner that was soothing:

"You know we used to enjoy sex. I mean we're not getting any younger but it was an important part of our relationship and it affected him badly. But now we've learnt how to know when I feel I can cope with it. I just give him this look and he knows that tonight we can try. I mean we can't be as energetic but in some ways that's better, there's a different intimacy to before"

In this way she typified these participants who felt that whilst they had lost forever one way of being, they had in fact gained something that was different and possibly an improvement. The need to be seen as sexually attractive and competent was restored, and they additionally acquired the feeling of being truly loved and understood.

The need to restore the sense of being physically attractive was also evidenced. When they had initially become ill they had taken less care in their appearance as they adopted the identity of someone who was ill. Society did not expect those who were ill to be taking care of their appearance or to look well. Having FMS created a dilemma for them which manifested itself over the course of the study.

Participants in the study were predominantly female and they described how prior to being ill they had given some consideration to how they looked. Section 5.5.3.2 described how the effect on their appearance had caused some of them to enact chaos narratives. For those in quest the persistence of their symptoms and the information they acquired about the nature of FMS caused them to consider the dilemma of how to present themselves to family, friends and the medical profession.

The nature of the condition and the symptoms experienced caused them to often feel older than they were. A number of them had gained weight as a result of the inactivity imposed as they adjusted to living with FMS. They told of a desire to remain attractive and retain their identity but had to increasingly consider the cost of this. Those actively re-engaging described how they had become more aware of their diets and were exercising where possible but in a paced manner. This was evidenced by participant 8 in her final interview:

"The last two times we spoke you talked about how you felt uncomfortable in clothes because of the weight you'd gained. Have you done anything about that, or how do you feel about that now?" CJD

"I've always enjoyed my clothes, shopping, putting my make-up on and looking nice. And now I'm beginning to feel a bit better and getting used to living with this I've started to come to terms with it. I'm also trying to watch what I eat and if I can get out for a little walk. I can't do running or aerobics but doing a bit more and not eating so much, I think that's helping" Participant 8

This was in contrast once more to those that had actively disengaged and reconciled themselves to an image of being overweight.

A potential conflict between how they presented themselves and how this was perceived and interpreted by other people was frequently talked about. Initially they

emphasised that they often looked well to 'outsiders'. Those that had actively disengaged became increasingly less concerned with how they looked and portrayed themselves to the 'outside' world. FMS had absolved them of the responsibility to 'make the effort'. The physical energy that would need to be expended to maintain their former appearance on a regular basis was too great. There was also a perception that they were less likely to receive external help if they seemed to be managing and 'looked okay'. They relinquished this former identity and in adopting the identity of a patient with FMS they considered they were absolved of the responsibility to present themselves according to a particular physical ideal.

This was in contrast to those actively re-engaging who sought out strategies to help them maintain their appearance. The occasions when they would need to present themselves in this way were carefully chosen and time was put into ensuring this happened. Where there was a need to do this on a regular basis e.g. going to work, they made adjustments to facilitate this. Hairstyles were changed to make them easier to manage, and clothes chosen which were comfortable but smart. When they were discussing how they planned for a special occasion they highlighted how they would plan the day so they could pace their activities. Participant 18 described how she was planning for her sons wedding:

"And going back you said you have your son's wedding approaching. Have you got your outfit? I know before when we spoke you mentioned you used to like to go out and get nice clothes and things" CJD

"I haven't got my outfit. It takes a while to actually motivate myself to go shopping, and when I do go I feel panicky. Before I'd plan a days shopping with my sister, have lunch. Now, I'll just get it one day when I feel like it. I know I've put weight on and because of that I don't always feel like it. I'm not going to let myself get upset about it. I just feel one day I will go and get an outfit. Maybe I'll have to go another day for the

other things, the hat, the shoes, handbag. But if I stress about it it'll just make things worse"

This group appeared more reluctant to be seen as ill, although this created a dilemma for them. If they did not look ill it was possible that their symptoms and how they were feeling might be misinterpreted. Everything was chosen to maintain an acceptable appearance in the least time consuming way. There was a strong belief that they should avoid a situation where they no longer made the effort to look good. This would impact on how they felt about themselves but also how others might see them – as old, and as having given up.

#### **5.6.2.5 Illness as a positive life event**

The theme 'illness as a positive life event' was only evident in those narratives dominated by quest and only witnessed as the study progressed. Acknowledging benefits conferred by the experience of living with FMS appeared to be instrumental in helping individuals to come to terms with their new lives. At the beginning of the study none of the participants were able to concede that there was anything positive to be borne by the experience of having FMS. This held true for the majority of the time whilst the study continued. However, by the second and third interviews some of the participants had begun to reflect and consider the impact that having FMS had had on them. Whilst they would have preferred to have continued to live their lives without it they were able to concede that there had been some benefits.

The participants describing a quest narrative identified the opportunity FMS had provided to stop and reflect on life. For the most part the illness had been an unwanted intrusion that had denied them the ability to live their ordinary lives. Having FMS had necessitated most of the participants in quest retreating from the totality of their previous lives whilst they waited for a diagnosis. They had then begun the process of adjusting to life with FMS and this provided them with the opportunity for reflection. Participant 8 highlighted this in her final interview:

"And can you think of any benefits of having fibromyalgia?" CJD

"Well you wouldn't wish it on anyone. But it does make you look back and think about the rushing around that you used to do, and looking after the kids. And you know you think about how you're glad that things are turning out okay now for everyone. And I can be there to help them (*the children*) with the grandkiddies which I couldn't have done if I'd still been at work. And with what happened in the past (*one of her children had been addicted to drugs*) you're just glad you can be there"

In doing so they were able to bear witness to both the losses and the gains that having an illness such as FMS had conferred upon them. Being diagnosed and living with FMS had given them the opportunity to relinquish some of their roles either voluntarily or involuntarily, when they realised they could no longer fulfil them. For a few of them (P1, 15) this was then accompanied by the chance to enact aspirations they had had for some time; previously they had denied themselves this through a combination of both circumstance and fear. Now they embraced the new opportunities presented to them. For others, especially those in disengagement, it provided a chance to opt out of roles and responsibilities that they did not enjoy.

The narratives demonstrated how being diagnosed and living with FMS caused many of them to address other unsatisfactory aspects of their lives. This wasn't always done to identify causation but to look at how life could be better in the present and future. Common areas of life that were discussed were relationships with partners, family and friends; work; health and fitness. Participant 1 typified this.

She had been subject to physical abuse as a child by a family member. In the initial interview for the study she had briefly discussed this but dismissed its relevance on her current life. She had also wanted to reject the illness identity of FMS at this point. Over time she appeared to acknowledge the changes that having FMS had facilitated.

Within the third interview she described how she had contemplated the abuse further and wanted to acknowledge that this had happened and discuss it with other family members. She doubted it had any direct relevance to her having FMS but conceded that it was now affecting her life with FMS. She discussed how having FMS had enabled the contemplation of a new present and future life; she wanted to expose this past life and reconfigure it with the abuse visible:

"You were talking about the abuse and how you didn't think it was anything to do with the fibro' but now you don't know?" CJD

"I don't know if it is. But a lot's gone on and it's made me think about it and maybe keeping it locked away hasn't helped. I don't know. But I think I now want to do something about it. I've spoken to my mum and she's sort of said 'what's the point after all these years' but I want to talk to him (*her abuser*) about what he did"

Other benefits were conferred to the participants who had maintained their relationships with their partners. They acknowledged how living with FMS from its onset to the end of the study had challenged different facets of their relationship. These included: feelings of doubt of credibility; an increased burden on partners who had to work harder at home and in paid employment; a change in levels of physical intimacy. However, they universally described how FMS had brought them closer. There was an increased emphasis on communication and acknowledgement of the support and the role that each played in sustaining the relationship and life together. While sexual relationships had diminished this was replaced by closer intimacy engendered by other types of physical contact e.g. a gentle hug, and greater consideration for each other.

It is important to highlight that whilst these gains were described, this study failed to identify anyone who was glad to have FMS. However, for those depicting the quest narrative, over time and to varying degrees, they were able to acknowledge their

losses and bear witness to the opportunities it had given them socially and psychologically.

## **5.7 Conclusion**

Section 4.5.3 introduced the role that narrative analysis can provide in gaining an insight in to the experience of living with illness. The results from this study suggest that the illness experience of participants with FMS can be explained using the narrative typologies described by Frank (1995) of “quest, chaos and restitution”. Initially these narratives were linear and followed a chronological sequence moving from restitution to chaos. Restitution remained the preferred narrative for all and the desire to both tell and hear this narrative rarely left, but was never enacted. For most participants it will lie either dormant or barely visible until a new hope of cure resurfaces.

After restitution and chaos the majority of participants in this study then told a quest narrative that comprised them either actively engaging (the majority) or disengaging (the minority) with life. A small number  $n=6$  instead told narratives where chaos dominated. These narratives whilst at the forefront of the participants' stories were always shared with one or both of the other narratives and this was usually determined by what was happening either with their illness or in the rest of their lives.

The next chapter will give some evidence of how reflexivity has been used within the study with particular regard to the researcher position. Chapter 7 will discuss further the findings of this study in light of both previous and more current research.

## **CHAPTER 6**

### **REFLEXIVITY AND THE RESEARCHER POSITION**

#### **6.1 Introduction**

The methodological and philosophical perspectives that have informed this study have highlighted the concept of the interview as a social interaction and the product of collaboration between the researcher and the participants. It is acknowledged (Manderson et al, 2006p.1318) that "understanding the multiple factors that shape the relationship of the interviewer and interviewee, in turn influencing the quality and content of information, is a significant task in interpreting research data". It is my belief that my personal and professional identities within the research study had a considerable impact on the study and this was evident from the pre-research stage through to data collection and analysis.

Reflexivity is considered a tool that "the researcher engages in an explicit, self-aware meta-analysis of the research process. Through the use of reflexivity, subjectivity in research can be transformed from a problem to an opportunity" (Finlay, 2002 p.531). Narrative research is acknowledged as requiring the researcher to make transparent the relationship with the participants within a study and to consider the how the researchers own identity, knowledge and beliefs have influenced the study design and method (Holloway and Freshwater, 2007).

This chapter will demonstrate how reflexivity has been used in this study to contextualise the study findings. It will also be used to acknowledge the strengths and limitations of the study allowing the results to be considered within this frame of reference.

#### **6.2 Pre-research stage**

It is suggested (Finlay, 2002) that reflexivity should be evident from the beginning of the research process, when the research question is created. This allows the opportunity to examine the rationale for the study and any pre-existing beliefs that



have the potential to affect the study process or outcome. Section 1.3 detailed how when the study began I was working as a lecturer-practitioner within the musculoskeletal speciality and how the initial research question had been the product of discussion with a colleague who was interested in conducting a research trial, in FMS, in primary care. I had little experience of treating/managing patients with FMS: although I did occasionally come across them in my practice, it was usually when they had been referred for the management of another musculoskeletal problem. I had limited knowledge of FMS and it was my opinion that this was a condition that generally benefited from management with tri-cyclic anti-depressants combined with chronic pain management. I was aware that amongst clinical colleagues (medical and allied health) these patients were often considered as 'heart sink' patients.

Section 1.3 detailed how I 'enjoyed' the challenge of managing patients where potential psychosocial barriers to improvement 'yellow flags' (Main and C de C Williams, 2002) had been identified. I was interested in how these individuals managed their health care problems within the context of their lives, and felt that this was an area suited to exploration using qualitative methods. This methodological approach had engaged me when I studied my PG Cert Res, and I was enthusiastic about an opportunity to utilise this method to answer a relevant research question.

Chapter 4 has detailed the evolution of this study from its original design into that which forms the basis of this thesis. To summarise after eight months of developing the research question and potential study design I went on maternity leave. This began abruptly and unplanned when I was admitted to hospital 7 weeks before my due date and whilst I was still at work. My studies were suspended for one year. On return a review of the literature led me to recognise a number of research opportunities that I had failed to see before: there were no longitudinal studies exploring the experience of living with FMS; there were no published studies in the UK; and that using qualitative methods alone could provide the opportunity to investigate this phenomenon in depth. I was registered for my PhD as a part-time

student and this provided a unique opportunity to be able to consider introducing a longitudinal design, frequently absent in studies of illness experience. The research question and study design were changed accordingly.

My professional identity as a physiotherapist was a strong influence in my decision to adopt the perspective of pragmatism within this study. The publication of qualitative research studies continue to be in the minority in physiotherapy and medical journals. At the outset of this study I had a strong commitment to producing research that was robust and meaningful to physiotherapists and doctors that was not reliant on understanding the different traditions of qualitative research methods. Pragmatism and its many commitments, in particular to a truth that should have a practical and useful effect, allowed me to do this.

At this stage in the research process I was aware of the multiple roles I had both professionally and personally. I now consider I was naïve in my belief that it would be possible to keep these roles separate. I was performing and balancing the duties of lecturer, clinician, researcher, wife and mother simultaneously and it became evident early on that this would not be as clear cut as I'd imagined, for all parties concerned. I had failed to consider in sufficient detail the impact that my many roles would have or, that they might change during the study.

### **6.3 Data collection and analysis**

It was when data collection began that the many issues surrounding my position within the research study precipitated. It is important to highlight that the tensions created by my multiple roles had both positive and negative consequences. Reflexivity has allowed me to consider the form, content and impact of these throughout the research process. These will now be described within the contexts of practical issues, the researcher as research tool, and professional identity.

### 6.3.1 Practical issues

One of the benefits of being a practitioner researcher was that it gave me access to Consultants who were able to help me identify potential participants for inclusion into the study. The main practical issue that arose was concerned with the time constraints and pressures imposed by my many roles. As a lecturer/practitioner I had been accustomed to the time constraints and pressures of working within a role that had commitments to two different areas of employment, and balancing this alongside my life at home. I worked full-time and for the duration of my PhD study was allocated a day a week for research activity.

My clinical days were the same two days a week and it was not possible to utilise this time for the purpose of my study. I had the duties required of my lecturer role two days a week to accommodate alongside my research studies in the remaining three days of the week. However, working around my lecturing commitments I could be more flexible about my availability for my research activity to take place. To meet the needs of study participants it was not possible to confine data collection to a single day a week, resulting in a balancing act to satisfy the responsibilities of all the roles.

This inevitably created conflict and was most apparent when participant 14 was over an hour late for her first interview. She arrived as I was leaving the office: she had struggled to find the building and it had taken over two hours for her to get there. I agreed to return and conduct the interview, aware that I only had 1 hour to do so before I had to leave to go home. I reflected on this later that day and the account from my journal is detailed below:

#### ***Summary of reflection after interview 1 participant 14, 7.6.5***

*"Did I do the right thing? I didn't feel as relaxed. Felt mixed feelings: slightly cross—she hadn't checked out where she was coming to and not allowed herself enough time. We were okay for time but I felt the time pressure throughout the course of our chat. Why had I not asked her to come back*

*another day? I was worried she might not come again: I know the difficulties that recruiting subjects can pose and feel really grateful to everyone who agrees to take part.*

**Points to consider:** *Allow some extra time in case this happens again. I will have to especially vigilant when I read/listen to this transcript: did I rush her? Did I give her enough time to answer? Did I ask her any more closed questions than I would normally have asked?*

I became increasingly aware that being a part-time researcher created time conflicts and these were heightened as the study proceeded and analysis and writing began.

In order to be reflective throughout the study I would record my thoughts after an interview had taken place. This took place immediately, on my return home or to the office, to try and ensure my recollections were reliable. In the week following an interview I would then take the time to reflect on the interview and the notes I had made. My considerations at this time were focussed around: 1) how did I think the interview had gone; 2) were there any new areas for discussion arising that needed following up either in the subsequent interview or in interviews with other participants; 3) were there any areas emerging that I needed to explore further in the evidence base; 4) did I need to consider extending my sampling strategy; 5) was there anything I needed to act on as a result of the interview e.g. when I sought advice from the Consultant regarding participant 13 disclosure of suicidal thoughts.

As interview data was gathered it was necessary to listen to the data and begin preliminary analysis consistent with the stages of iterative thematic analysis. In keeping with this analytic process it wasn't methodologically appropriate to complete data analysis after each phase had been completed but to continually apply and revisit the themes and theoretical assumptions that were being drawn. Accordingly I had to revise my initial thoughts of completing data collection in large 'chunks' but perform it

regularly with adequate time for analysis and reflection in between. This continued when the analysis moved to narrative thematic analysis.

This contributed to the study taking place over a longer period than anticipated together with other occasions when time away from the study occurred due to both work and personal commitments. Section 1.3 detailed how during the course of this PhD I changed my job on two occasions: in 2006 I returned to full-time clinical practice and in 2010 returned to a full-time position as a lecturer. In addition in 2009 I separated from my husband, having to move house and settle my then 6 year old daughter into her new home situation. The opportunity to study effectively was fragmented and resulted in an extension of one year to writing up of the thesis. There were advantages and disadvantages to the planned and circumstantial gaps in the conduct and write up of this thesis. When immersed in the study it appeared easier to remain 'in the flow' of interviewing and analysis. At these times I seemed to find it easier to remain in the identity of researcher/interviewer. I rarely needed to refer to the interview guide and could remember more easily the themes that I wanted to discuss and was able to see the issues arising from the data.

At times though it seemed as though I was too close to the data; when I was distanced from the data there was it seemed an opportunity for reflection and consideration of the larger picture. It was at these times, and in particular later in the study, that development of the theoretical model to explain the findings gained greater clarity. I would revisit the data to ensure that this model had not been generated by my desire to find something that 'fitted' but instead adequately explained the findings. I continually acknowledged the possibility that this model offered one explanation but that others may have been present. I searched for these and in keeping with the theoretical perspective of pragmatism and my role as a practitioner/researcher aligned myself with the explanation that best suited answering my research question and met my purpose i.e. to understand the experience of living with FMS and help clinicians understand it in a meaningful way.

### **6.3.2 The researcher as research tool**

Interviewing and focus groups are common methods that are utilised to explore illness experiences of patients and have been the focus of previous research studies that have explored the experience of living with FMS (Madden and Simm, 2008).

Interviewing is considered a social interaction and the product of the relationship and the encounter between the researcher and subject (Mason, 2002; Nunkoosing, 2005).

It is suggested that reflexivity can help develop an understanding of the position of the researcher within the context of the interview and that prior knowledge of a subject area in some situations can be "an essential pre-requisite for situated understanding and positive action" (Freshwater and Rolfe, 2001).

Throughout the process of data collection I considered how answers to questions were not just a response given to provide required information but they were considered and framed according to the context within which they were given. I considered that the responses of participants were influenced at any one time by the different identities I presented to them. It appeared that they did not consider my identity static or single faceted, and this seemed to change dependent on the focus of the conversation we were having at any one point in time. For example, when we were discussing directly health related issues they appeared to answer as someone who had insight into what it was they were describing based on professional knowledge. This contrasted with when we were discussing issues about relationships when they appeared to talk to me more as one of their peers; I now had insight into what they were describing because of my personal experience of life.

Similarly I was able to consider that whilst the participants had chosen to frame their answers or stories in a particular way, so I had chosen to ask questions in a manner that might elicit a particular answer. I became conscious that this was influenced by the data emerging and literature that I was reviewing but also by curiosity resulting from both my personal and professional roles. An example of this is presented in my

considering how I responded when participants recounted their experiences of physiotherapy:

***Reflection after 1<sup>st</sup> interview with participant 3, 11.3.5***

*"Need to look at how I respond when I am discussing physiotherapy in the interviews. I felt quite defensive when P3 said that she had physiotherapy and didn't see the point of being referred for this complaint. My initial reaction was to try and justify why it might be a good idea for her to go, and almost to defend physiotherapy. I didn't and was able to step back in to the role of researcher and ask her about her experience instead.*

***Points to consider:*** *I need to be conscious of not passing judgement. I need to remember that my role is to try and find out what normally happens and why"*

Prior to starting data collection I had given little thought to how my own personal experiences might shape the interview, or how the interviews might influence me. The literature review (section 2.2.2.6) described an association between individuals presenting with FMS and a previous history of abuse. At the time of the study I was in a relationship where spousal abuse was taking place and during the study this led to marital breakdown. This was a subject area that had not previously impinged on my professional life: it was a rarity for sensitive topic areas to be discussed in therapeutic encounters and I was unprepared for how I would react when they were brought up. At the outset of the study I had discussed with the Rheumatologists how we would manage psychological distress in the participants if it arose. In hindsight I had not considered in detail how I would deal with the intricacies and disclosure of personal and sensitive information during the research interview.

During their first interviews participants 16 and 17 disclosed that they had been abused by their partners and described incidents of physical, sexual and psychological abuse that took place. Some of their experiences were similar to my own and resulted

in me having mixed feelings when I initially had to confront these areas of conversation. On a personal level I felt distressed and this continued for some time after the interview. I did consider, given my alignment with the principle of reciprocity, the possible merits of sharing my own experiences with them and whether this would facilitate discussions between us. However, I felt that this had the potential to detract from the conversation we were having where the focus was on them and their experiences. I did reflect and consider that my own experiences provided 'insider knowledge' of this aspect of their lives: it allowed me to have empathy with them and to approach discussing it with the sensitivity and understanding that it merited.

I further reflected on why they had chosen to disclose this information, some of them for the first time, and how this might also have impacted upon other interviews I had conducted. Previous research (Manderson et al, 2006; Hamberg and Johansson, 1999) had identified that age, class and gender can influence the interaction in research interviews. It is suggested that women facilitate the 'opening up' of emotional issues in both genders and older interviewers utilise their own life experiences when engaging with interviewees to demonstrate common backgrounds or adopt appropriate conversational styles (Manderson et al, 2006). This contrasts with research into unexplained musculoskeletal pain. Hamberg and Johansson (1999) reported that information given in research interviews is influenced by the gender and professional status of interviewers and female physicians might have the most difficulty in conducting interviews with female participants as a result of "gender related expectations".

I aligned my own experience with that of Manderson et al (2006). I considered myself an 'older' research student, and shared with them a number of life events with the participants: work, marriage, divorce, children, family bereavement, and mental illness. I wondered whether this shared history had engendered the notion of shared understanding. I also postulated whether I had provided them with the opportunity to think and reflect on their experiences, and then created a safe environment in which



they were able to disclose their experiences (Holloway and Freshwater, 2007). This belief that I was perhaps creating a secure atmosphere exempt from judgement was reinforced when participants disclosed further sensitive and personal information including drug use and intimate details of relationships.

In her first interview participant 23 described how she had been having an affair with a married man. The text presented here whilst it does not detail body language including changes in the intonation of my voice, I hope provides an example of being non-judgemental:

"You wonder if this is the result of what had happened to me. I mean I know it didn't happen at the same time, but I'd been seeing someone who was married, and he was in a car crash. And because I was the 'other woman' I couldn't go to the funeral, I couldn't grieve" Participant 23

"And how did that make you feel?" CJD

"Rotten and well empty. And you wonder afterwards if this is because of that. Your bodies way of showing how hard it's been" Participant 23

This excerpt further demonstrates how I utilised questioning to reflect back feelings to elicit the emotional aspect of the interview as well as the content to gain greater insight into the illness experience (Holloway and Freshwater, 2007).

Entering in to the research field I had considered that my expertise in questioning patients in therapeutic interviews would equip me with the necessary skills to conduct the research interview (Bulpitt and Martin, 2010). Within the research interview I was increasingly conscious of the need to ask questions that were both questioner centred and participant focused (Holloway and Freshwater, 2007). This ensured that I was able to gain answers to questions that I had considered important but also enabled the

participants to disclose information that was relevant and important to them. On reflection I re-positioned myself as a novice when it came to interviewing patients about their illness experiences and perceptions.

The growing awareness within physiotherapy of the bio-psychosocial model (Engel, 1977) had given me some insight in to the psychosocial impact that illness can have on an individual, and an individual on their illness. However, time constraints in my own practise had placed much emphasis on extracting a history, performing an examination and determining what the biological problems were that could be dealt with. Questioning while open had been very similar to using a structured interview guide with questions and issues relating to diagnosis and condition management being the prime focus of the interaction.

The research interview challenged my skills as a researcher. Now the emphasis was on allowing the participant the opportunity to disclose what was important to them, and giving them the time and encouragement to discuss it. Within the first couple of interviews I was aware of trying to 'steer' participants back to the guide to fulfil my objectives. After a couple of interviews the realisation that important issues were arising that I had not considered e.g. how their previous experience of health and illness was influencing their current experience. I gained confidence in allowing the participants to tell me what they wanted with the knowledge that this would yield more relevant data.

Similarly at the outset of the study my own position and experience, informed by the evidence base (Chapter 2) and tacit knowledge, had provided an insight into potential themes that might arise out of the data. Initially it was easy to 'see' these themes within the data: I also believe that intuition helped allow me to see themes that I had not considered at the outset. These were embedded within the data but I consider that it was my own researcher position, combined with a continual re-examination of research literature that enabled me to see these themes as they emerged. Once

visualised, they were tested by application to the data that had been collected as well as existing theory for validity.

The explanatory model presented in this study of illness narratives based on the work of Frank (1995) is I believe further influenced by my researcher position. This model allows me to provide an explanation that can be understood by clinicians and utilised in their interactions with individuals that have FMS. It is an explanation that is not reliant on prior knowledge of medical sociology that most clinical physiotherapists might not have. It can help fulfil an objective of the study, to help clinicians understand the illness experience of patients with FMS. As a clinician researcher I have a strong commitment to producing research that adds to academic knowledge whilst also being concerned with how that knowledge can be used locally and professionally.

Reflection on my position within the study has highlighted the different roles and identities adopted during the study. These roles were not inflexible and this position was aligned with the perspective that "it is possible to choose different positions and practices within a discourse, depending on the circumstances in the actual situation and interaction" (Hamberg and Johansson, 1999 p.459). Dependent on the nature of my interaction (either with the data or participants) my different roles and identities would shift from the foreground to the background, and sometimes multiple roles were adopted simultaneously. To some extent this 'mirrored' the kaleidoscope effect that I have described within the narratives of the participants whereby my position could adopt one dominant form but then could rapidly shift so another became visible..

Within my own researcher narrative it was possible to witness changes in both how I positioned myself, and how the participants positioned me, that were determined by the different discourses. This reflects the poststructuralist paradigm that encourages choice to meet the needs of a particular discourse (Davies and Harre, 1989).

Invariably this resulted in adopting the role of physiotherapist/health care practitioner when discussing aspects of care, that might shift between my different identities as a

woman (mother, wife, abused) when talking about their experiences of coping within the home environment and researcher when talking about living with FMS. These positions/roles were rarely homogenous and could move, responding to a particular situation, within days or seconds.

### **6.3.3 Professional identity**

Previous research (Fraser, 1997; Richards and Emslie, 2000) has identified some of the ethical and role conflict issues that can affect the practitioner researcher. A number of these were pertinent to this study where I was operating as a 'hybrid' practitioner researcher made me consider the implications of my professional identity within this study. In comparing the subject areas that participants are likely to discuss within interviews Richards and Emslie (2000) highlighted how respondents in their study were more likely to talk about health related issues with a health care practitioner and broader topics with a sociologist.

A weakness of this study is that respondents engaging with each researcher had potentially different areas for the focus of discussion at the outset. Fraser (1997) identified the potential role conflicts that being practitioner and researcher can pose, whilst conducting research into the development of a new midwifery programme. This highlighted the difficulties in keeping roles separate and of not betraying trust in participants when sensitive information is disclosed.

At the outset of this study I had considered that questions about FMS might arise, that would require my practitioner knowledge to answer. I attempted to make clear my identity by explaining that I was present in the interview as a researcher and it was not my intention to treat or influence their individual treatment. However, questions did arise that I tried to answer as truthfully and concisely as possible. In aligning with the feminist principles of research methodology that had influenced the study I decided to: (a) answer any general questions about FMS at the end of the interview and (b) give them an additional information leaflet. This was given at the end of the first interview

and there was no evidence from in-depth readings of their interviews that this had altered their understandings. This combination appeared to work well and a small period of time was generally used to discuss any new information they had questions about e.g. treatment they'd heard about on the internet.

This was with the exception of participant 23. Following her first interview she requested a report in support of her Disability Living Allowance Appeal. The following excerpt from my researcher diary details my reflection on being asked to provide this information:

***Reflection after being asked for DLA report for participant 23,***

*"Found it difficult explaining to P23 about not being able to provide a report for her DLA appeal. I can understand why she wants to appeal and in fact she probably has a case. It's just that I'm not the person to do it: I don't have all the information I would need to do this properly and I haven't examined her. I suspect that if I don't do this she won't stay in the study. I know it's important to try and establish and maintain a good relationship with them (the participants) but there have to be limits to what I am prepared to do. It's taken me a bit by surprise as no-one else has demonstrated this confusion with who I am but I will have to be more aware of it."*

Whilst as a practitioner I was used to writing such reports, I did not consider myself to be in the position of *her therapist*. I did not want to alienate her with a refusal but it was not within my remit as researcher to engage with this process. Following discussion with my principal supervisor (Mark Avis) I provided a report that detailed the information that had been disclosed to me, but emphasised that it was not clinical data. She dropped out of the study, with no further contact.

Throughout the study I had a growing consciousness of how my professional role had the potential to confer power, knowledge and status within both the academic and

health care settings. Whilst I had considered how this might facilitate the interviews (with participants envisaging me as someone with a shared knowledge and insight of what they were describing) I had failed to consider in depth how participants might interpret this to benefit them. It was possible that she had seen our relationship as one where rapport and understanding had been established, having disclosed personal and sensitive information. I looked back through the transcript to ensure I had not misled her about my identity, and had to consider that the identity I presented might not equate to the identity seen by participants.

Further evidence that participants perceived me as practitioner was provided when they described that part of the motivation for them entering the study was to 'find out more about their condition'. I attributed this to describing myself "as a physiotherapist interested in finding out what it is to live with fibromyalgia" and did consider whether I would have had the same response had I introduced myself as only a researcher, or if I had been a social scientist. I considered it would have been unethical to deny my professional status. However, I also judged it to be unprofessional and unethical to answer questions about their own case management. Instead I encouraged them to raise concerns with whoever was managing their condition.

#### **6.3.4 Theoretical perspectives**

Since completing this research study I have had the opportunity to reflect upon theoretical perspectives that I explored and adopted, and how I have incorporated them into my own philosophical perspective. As a product of engaging with the research process I increasingly consider the epistemological foundations of a study and knowledge generation, challenging some of my pre-conceptions of what can be considered as 'truth' in qualitative research. This has led to the rejection of methods and methodology that adhere to specific qualitative traditions. Instead I embrace the beliefs that: methods and methodology should align with research questions and, that it is necessary to demonstrate credibility within all elements of the research process.

Utilising pragmatism as one of the epistemological foundations of this study I endeavoured to produce theory that would help to explain the experience of what it was like to live with FMS. I believe that I achieved this and that in doing so I was able to present an explanatory model that would help clinicians to recognise the narrative preference of their patients, and consider how best to engage with them. On reviewing the findings it is also possible to see how an alternative theoretical position of feminism could have been adopted.

Feminist research is primarily concerned with "research that relates to women's position as that of an oppressed social groups and which adopts a critical perspective towards intellectual traditions rendering women either invisible, or subject to a priori categorizations of one kind or another" (Oakley, 1993 p.245). I have previously described in Chapters 2 and 3 the commitment of this study to feminist principles that related to the conduct of this study. This and the narrative approach taken in analysis have provided some insight into the silencing of women with FMS in health care and society. However, feminist perspectives were not adopted during the analysis and on reflection a number of key issues can be seen embedded within the data that suggest women with FMS experience oppression and are treated unjustly.

Areas that suggest the adoption of feminism as an analytical lens included:

- The diagnosis and management of FMS for the participants predominantly occurred within the framework of a biomedical model of healthcare that is patriarchal.
- The participants gave many examples of difficulties in being diagnosed and having their voices heard once diagnosis was made.
- The impact on relationships was widespread and on some occasions destructive but little if any opportunity was given to express this or support them.

- The invisible nature of the condition presented dilemmas in how to present themselves: they had a desire to take care with their appearance but this then had the potential to either discredit or deny how they were feeling.

Given the above observations it is possible that further analysis of the data from a feminist perspective may give rise to an alternative discourse about the experience of living with FMS.

#### **6.4 Post-research**

In the post-research stage I have been able to reflect on my individual identity and the impact that conducting this research has had. At the beginning of the study I considered myself a novice researcher: whilst I had received research methods training I had never carried out a research study. I have now achieved this and find myself in the position of being one of two post-doctoral staff in my department. The external ratification of my achievements affords me credibility as a researcher within a Division where research output is considered to be poor. I no longer identify myself as a clinician and teacher who has been doing a research study. I have emerged as an academic with teaching and research commitments, underpinned by a wealth of clinical experience. This has afforded me the confidence to have greater participation in discussions surrounding research, and to network within the wider School and University.

In addition to impacting on my confidence as an academic and researcher this programme of study has impacted on my position as a woman. Exposure to discussion of sensitive issues that I myself was experiencing e.g. spousal abuse, challenged the perceptions of my own identity and life. Whilst listening to the experiences of the participants who shared their stories I began to challenge my own perceptions of how I was 'coping' with my own life experiences. The way in which some of them had 'risen above' their life problems and the courage they had shown



was an inspiration. I also saw how life might be if I chose to ignore what was happening.

During the study I left my marriage and divorced my husband. Since then there have been ongoing difficulties and I have been subject to further verbal abuse and intimidation. I no longer see myself as disempowered and believe 'I deserve better': I am now able to confront my abuser from a position of empowerment. Whilst I cannot concede that this has been the product of my engagement in research alone, it has played a significant part: I have been able to witness first hand what I can achieve when I apply myself.

### **6.5 Strengths and limitation of the study**

In considering the results, interpretations and relevance of the findings presented in this thesis it is necessary to reflect upon the strengths and limitations of the study. It is my belief that this study makes a unique and substantial contribution to understanding what it is like to live with FMS. Evidence of reflexivity will be demonstrated by thorough consideration of how the aims and objectives of the study were met, and rigor was achieved.

The study aimed to answer the research question "What are the experiences of individuals diagnosed with fibromyalgia syndrome and do they change over time?"

The objectives of the study were:

- To identify and recruit individuals newly diagnosed with FMS by a Rheumatology Consultant in a Secondary care Setting
- To gain local ethical and R&D approval
- To use semi-structured qualitative interviews to capture the lived experiences of individuals newly diagnosed with FMS
- To explore whether time mediated the experiences of diagnosis and living with FMS through interviews used at three time points: baseline (within 3 months of diagnosis), at 1 year and 18-24 months
- To identify what if any meanings could be inferred from their experiences

- To develop a theoretical model to explain the lived experience of individuals with FMS that might facilitate their holistic assessment and management by clinicians

The aims and objectives of the study have been achieved and demonstrate the application of a sophisticated understanding of qualitative research techniques. This has resulted in an iterative and emergent design that has continually evolved in order to best answer the aims and objectives. In addition it has led to the development of a supplementary objective:

- To investigate how illness narratives offer an explanation for the illness experience of those with FMS

23 participants were recruited within 3 months of being diagnosed with FMS by Rheumatology Consultants. They were interviewed on up to three occasions making it possible to explore the effect that time has on the experience of living with FMS. This is only the second research study into the illness experience of FMS in the UK (Madden and Sim, 2006): the previous study primarily addressed the experience and meanings attached to diagnosis. All previous studies investigating this phenomenon have recruited patients that have been diagnosed for a number of years, creating problems of recall: this was minimised in this study as participants had been recently diagnosed. There have been no previous studies exploring the illness experience of FMS longitudinally; this approach allowed the unique opportunity to explore the temporal aspect of illness experience and facilitated the development of trust and rapport between the researcher and the participants.

Analysis within the study underwent transition from an iterative thematic to narrative thematic approach in order to best address the aims and objectives. An understanding of the meanings attached to the illness experience of FMS and the development of a theoretical model to explain the findings has been achieved through the use of qualitative interviews and a narrative thematic approach to data analysis. This model

is based on concept of the narrative typologies of 'quest, chaos and restitution' described by Frank (1995). The data within this study was explored against other intellectual perspectives prior to the development of this explanatory model.

In the last chapter additional evidence to support the results and their interpretation is demonstrated through: (1) the comparing and contrasting of findings against other studies that have utilised Frank's model and, (2) the examination of the findings against what is already known about the illness experience of FMS. Further enhancement of the reliability and validity of the findings has been enhanced by the use of critical reflection that has demonstrated the movement from description to interpretation, and made transparent the integration of data, researcher knowledge and experience and existing evidence.

A detailed discussion of the reflexivity and the researcher position has been presented to further enhance understanding of the decisions and actions that took place. It is my belief that the unique position of the 'hybrid' practitioner researcher in this thesis combined with my own personal background to give a unique access to the participants and their experiences. No previous research studies have investigated the illness experience of FMS from this perspective.

The design of the study where the researcher is the research tool does create the possibility of bias, and it is possible that the participants would have responded differently had my gender, age, social and professional status been different. Given the longitudinal nature of the study it is possible that the findings were partly a product of reactivity: the Hawthorne effect and or the novelty effect. (Onwuegbuzie and Leech, 2007). Being involved in a research study and having someone listen to their stories were unique events for the participants and may have contributed to what they were willing to disclose. Each interview offered a participants' individual perspective at that moment in time and it is possible that this might have been different on another

occasion. The multiple interviews and lack of anomalies in their stories adds however to the reliability of the findings.

Given time constraints it was not possible to perform all the transcriptions but the possibility of errors occurring was reduced by reading the transcriptions whilst listening to the interviews. Similarly, time and a lack of funding prevented access to secondary validation of the analysis. Reading of the first eight transcripts by my principle supervisor was an attempt to provide an independent critique of the interviews (content and conduct) but further support was not feasible.

The sample size of this study is small and this has the potential to threaten the reliability and validity of the findings and restrict their generalisability. To help overcome this data saturation was used but it is still possible that further themes may have arisen if sampling had been prolonged. In addition the theoretical model presented has been tested against other contemporary studies using these narrative typologies or illness experience in FMS: the findings have been corroborated and this enhances their validity and reliability.

The sample included in this population was representative of patients that typically are affected by FMS. It was not possible to recruit more than one male, and therefore it is not possible to make any analysis based on gender and narrative typologies.

Additionally all of the participants were recruited from a Secondary Care NHS Trust, and been diagnosed within 5 years. Previous research (Madden and Sim, 2006; Undeland and Malterud, 2007) has identified that the process of diagnosis can be considerably longer: if this had been the case there may have been a difference in the temporal pattern of the restitution and chaos narratives. It is also possible that the illness experience might be different for those individuals that are diagnosed in primary care by their general practitioner, or who have the symptoms and are not diagnosed.

## **6.5 Conclusion**

The use of reflexivity is advocated as a tool that can enhance the trustworthiness and credibility of qualitative research (Holloway and Freshwater, 2007). Through reflexive analysis it is possible to make explicit the subjective and inter-subjective elements of the research process, and consider the influence that they have had on both the conduct and outcome of the investigation (Finlay, 2002). This chapter has sought to demonstrate how this has been used to enhance the understanding of the contextualisation of this study. The potential merits of the 'hybrid' researcher position have been discussed together with possible benefits of my own personal characteristics. The strengths and limitations of this study have been identified with the intention that this might help make transparent potential effects on the collection, analysis and interpretation of the data presented.

The final chapter will summarise the findings and critique them in the context of other relevant research, prior to drawing attention to the clinical relevance of the study and its findings.

## **CHAPTER 7**

### **DISCUSSION AND CONCLUSIONS**

#### **7.1 Introduction**

The aim of this study was to answer the research question 'what are the experiences of individuals with FMS and do they change over time?' This has been achieved through the iterative and emergent design that was adopted and has led to the identification of illness trajectories and narrative preferences in individuals that have been recently diagnosed with FMS. These will be summarised within this chapter.

The narrative presented by each participant in this study was influenced by their own unique experiences and perceptions, yet there were shared characteristics enabling the identification of narrative typologies consistent, challenging and extending those described by Frank (1995) of 'quest, chaos and restitution'. These narrative typologies have previously been utilised to describe the illness experience in conditions other than FMS (Travers and Lawler, 2008; Whitehead, 2006; Reynolds and Vivat, 2006; Thomas- Maclean, 2004; Ezzy, 2000). This study adds to the evidence base and the results of this study will be compared and contrasted alongside this existing evidence.

The illness narratives presented within this study were underpinned by issues of: diagnosis, identity and stigma, sick role and biographical disruption. These issues had been identified in previous literature exploring the experience of individuals living with FMS (section 2.3). The results of this study will be re-examined alongside this and more recent literature to provide additional evidence for the reliability of these findings and their potential transference to other settings. This will demonstrate that the narrative typologies presented provide a robust model for understanding the illness experience of FMS that might be replicated in other chronic illnesses. The potential relevance of the study findings will be discussed and future recommendations for research made.

## **7.2 Franks narrative typologies**

Illness narratives are acknowledged (Polkinghorne, 1988) as a means by which individuals' with chronic illness make sense of their life histories, utilising them to help recreate and integrate changes in self and identity. Chapter 5 described how the emergent nature of this study led to the use of narrative thematic analysis and identified the presence of the narrative typologies of quest, chaos and restitution (Frank, 1995). Adoption of the narrative approach in understanding the illness experience in FMS is unique with the exception of one previous study (Kelley and Clifford, 1997): the methodological rigor of this study was reduced with the findings largely descriptive and lacking the development of a conceptual or theoretical framework. The results of this study offer a unique framework for understanding what it is like to live with FMS that is conferred by the longitudinal design and the narratives that are presented.

The analytic approach adopted within this study shares with Frank (2001) the concept of both form and content being integral to the narrative. Common stories were identified within the illness experience of those living with FMS, and within these stories were shared themes or sub-plots that further served to characterise the illness experience. The findings from this study provides further evidence for the robustness of Frank's (1995) narratives, whilst proposing some limitations of Frank's original model that are highlighted in the proposed new sub-plot of actively disengaging. This will be described further in the discussion of quest.

Previous research that had utilised the narrative typologies described by Frank (1995) were identified and critiqued in section 4.5.3. The results from these studies will be referred to as further interpretation of the analysis of this study is described. Their findings combine with those of this study to reinforce that whilst the characteristics of quest, chaos and restitution are context dependent the plot remains the same. In addition they reinforce the finding that whilst one narrative might be dominant the

others can remain in the background and re-emerge as illness and life experiences change.

Three studies (Travers and Lawler, 2008; Whitehead, 2006; Reynolds and Vivat, 2006) explored the experience of individuals who had CFS. Subjects within their studies had been diagnosed with CFS between 6 months and 32 years ago, and included both men and women. This was in contrast to Thomas-Maclean (2004) who explored the experience of women with breast cancer diagnosed between 1 and 24 years, and Ezzy (2000) who investigated men and women with HIV, diagnosed 1-14 years.

Two of the studies were conducted in the UK (Whitehead, 2006; Renoylds and Vivat, 2006) with the remainder taking place in Australia (Ezzy, 2000; Travers and Lawler, 2008) and Canada (Thomas- Maclean, 2004), making comparisons with health experience less transferable given differences in state provided health care outside the UK. In all of the studies interviews were used to elicit the experience of living with chronic illness and these were performed on either one (Ezzy, 2000; Reynolds and Vivat, 2006; Travers and Lawler, 2008), two (Thomas-Mclean, 2004) or three occasions (Whitehead, 2006). Whilst two of the studies used more than one interview to gain rapport and trust, these were not used to explore temporal components of the narrative. Instead the temporal nature of the narrative was reliant on recall of events that had happened in the past. The theoretical and methodological perspectives were influenced by grounded theory (Travers and Lawler, 2008, hermeneutic phenomenology (Whitehead, 2006) or a narrative approach (Thomas-Maclean, 2004; Reynolds and Vivat, 2006; Ezzy, 2000).

### **7.2.1 Restitution**

Results from the study presented in this thesis suggest that all participants began with a restitution narrative. It was this narrative that they described when describing their previous experience of illness and reflected their expectations that with the onset of



symptoms, a cause would be found and a cure provided. Symptoms that symbolised the onset of their illness were familiar and unthreatening and interpreted within the context of their past of health and illness. Benign explanations were given and at this point they still considered themselves to be in good health. Medical consultations were sought if symptoms were either considered severe enough or persistent enough to warrant a medical opinion.

This was also demonstrated in those individuals with CFS (Travers and Lawler, 2008; Whitehead, 2006). Similarities to those with FMS were evidenced in the withdrawal from work, family or societal obligations as necessary in order to rest. This was in anticipation of symptom resolution and the ability to fulfil the 'plot-line' of 'tomorrow I will be better again' (Frank, 1995). This component of the restitution narrative appears to be representative of adherence to the 'sick role' advocated by Parsons (1951).

From the perspective of Parsons (1951), illness has the capacity to interrupt routine personal and societal obligations and has the propensity to be considered a form of social deviance. To avoid this Parsons (1951) proposed that the patient and doctor had rights and obligations to fulfil. The patient had the right to become ill and be exempt from normal role requirements, whilst being obliged to seek help and have the desire to get better. The doctor was similarly obliged to perform the appropriate duties and provide the appropriate remedy to ensure recovery took place.

The obligation of the patients to seek help and desire to get better was enacted throughout the restitution narrative and highlighted in the search for a diagnosis. Individuals with FMS initiated this process for the following reasons: lack of resolution of symptoms within the anticipated framework of rest and treatment; occurrence of additional symptoms; unexpected and inexplicable worsening of initial symptoms; increasing interference of daily function; and fear that something serious was wrong with them. This was also reflected in the experiences of people with CFS (Whitehead, 2006). Individuals with CFS and FMS endeavoured to find a causative explanation

within the framework of the biomedical model and, the appropriateness of this was reinforced with initial explanations offered by health care practitioners dominated by biomedical familiar explanations and remedies e.g. virus, muscular strain.

For those with breast cancer (Thomas-Maclean, 2004) and HIV (Ezy, 2000) restitution narratives did not emerge until diagnosis. It is not clear from the reports of either of these studies whether diagnosis was initiated by the subjects (and the result of symptoms triggering this) or through routine screening. Assuming the latter it is possible that on learning of their diagnosis restitution was dominant as it reflected the desire to enact the modernist perspective "that for every suffering there is a remedy" (Frank, 1995 p.80). Unlike those with FMS there would have been no ambiguity accompanying diagnosis of these conditions with the presence of objective evidence confirming the presence of medically recognisable disease, the severity of disease and prognosis.

In the absence of any diagnostic confirmatory tests and reliance on the fulfilment of diagnostic criteria (Wolfe et al, 1990), that have themselves been subject to scrutiny and doubt regarding their diagnostic utility, the search for a diagnosis became a struggle. This symbolised the transition to telling a predominantly chaos narrative. It is possible that with the adoption of new diagnostic criteria (Wolfe et al, 2010) that acknowledges symptoms other than pain in the experience of FMS this period of time prior to diagnosis might be reduced. However, still fails to address the lack of credence conferred to the diagnostic label of FMS.

Previous research (described in section 2.3.1) provides further evidence of the difficulties that patients experience in this period pre-diagnosis that is reinforced in a more recent qualitative interview study of 17 individuals with FMS in the UK (Madden and Sim, 2006). Receiving a diagnosis, and acknowledgment of their pain by medical professionals, has significance for patients. Prior to diagnosis familiar explanations such as muscle spasms are given but prove lacking as they "failed to acknowledge the

nature and authenticity of the experience" (Madden and Sim, 2006). Evidence of the struggle to be diagnosed and the trivialisation of symptoms is also suggested in an American interview study of 10 patients in the USA (Schaefer, 2005). These studies interview patients with a varying duration of time since diagnosis (1-30 years), creating threats to reliability of findings due to potential difficulties in recall.

With medicine failing to offer an adequate explanation or management strategy individuals in this study sought it for themselves. This was also true of those with CFS (Whitehead, 2006) and has also been reported in more recent research in FMS (Undeland and Malterud, 2007; Asbring and Narvanen, 2004). A Swedish interview study of patients with FMS and CFS (n=15) (Asbring and Narvanen, 2004) and Norwegian focus group study of patients with FMS (n=11) (Undeland and Malterud, 2007) reinforced the finding that self resourced explanations for symptoms were sought both prior and after diagnosis. Self-diagnosis was usually done utilising information in the media, and reflected the findings of this study. These samples were recruited from self help groups (Undeland and Malterud, 2007) or were already in receipt of treatment (Asbring and Narvanen, 2004). The presence of this finding in different populations increases its credibility and transferability.

Within 5 years all of the participants in this study had been referred on to Secondary Care and diagnosed with FMS. This contrasted with individuals with CFS (Whitehead, 2006) who experienced far greater resistance to being referred to someone who was able to make the diagnosis of CFS, taking up to ten years in one instance. Given the similarities inherent in the onset and presentation of these two conditions it is not possible to offer an explanation for why this difference is evident. It is possible that whilst FMS itself attracts debate as to its existence as a true 'illness' (Hadler, 2003), CFS has attracted much negative attention, present in the media with references to it being 'yuppy flu' and the product of a particular over-extended lifestyle (Whitehead, 2004).

For those with FMS restitution re-emerged as a dominant narrative when diagnosis was first made. Diagnosis reduced the turbulence that had been present, providing reassurance that nothing serious was wrong and initially offering hope that treatment could restore things back to how they were. In addition it alleviated the lack of credibility that individuals had experienced prior to diagnosis. Over time the meanings attached to diagnosis were modified and this finding is supported in further research (Madden and Sim, 2006; Whitehead, 2006). The diagnosis of both FMS and CFS bring further uncertainty regarding aetiology, treatment and prognosis, and both medical and societal ambiguity.

In acute illness and illness where there is known aetiology and patho-physiology, establishing a diagnosis supports the narrative of restitution through its potential to signpost treatment and prognosis. Acute illness poses less potential threat to an individuals' identity and biography and this is reflected in the restitution narrative as disruption to both is resisted. Diagnosis provides an opportunity to fulfil the 'tomorrow I will be better' (Frank, 1995) component of the plot. Recent research continues to support the multi-factorial explanation for causation in FMS (Nielsen and Henriksson, 2007) but there remains no confirmatory diagnostic test. This promotes the practice of medical practitioners being reluctant to provide a diagnosis (Blaxter, 1978) and reflects the experiences of primary health care consultations for those with FMS.

Being diagnosed offers the opportunity for individuals pursuing medical advice and support to gain credibility and reassurance through the provision of a label that confirms their status as an 'ill' person (Miele, 1986). Sceptics (Erich, 2003; Hadler, 2003) contest the existence of FMS or the value of labelling a condition that lacks definitive proof of organic pathology and whilst these arguments are old there is no evidence that they have changed. Diagnosis is considered to provide false representation that a cure is accessible or cause individuals to adopt the identity of the sick (Hadler, 1997).

The results of this study would support the concept of 'false hope' that might have been created when participants were initially diagnosed and contemplated the prospect of treatment. For some the realisation that this would not occur returned them to chaos. However, I would suggest that once participants were able to acknowledge that restitution was unlikely diagnosis was then used to support the movement towards a quest narrative. This created the opportunity to re-engage with their previous or a new life: adoption of the 'sick role' argued by Hadler (1997) was only found in two participants in this study who told told quest plots of active disengagement.

For those with breast cancer (Thomas-Maclean, 2004) restitution reflected the desire to return to normal and be healthy once more. Once treatment had been completed it was possible to return to a previous life and consider themselves to have a healthy body that could be taken for granted "an aspect of everyday life assumed by those who are healthy" (Thomas-Maclean, 2004 p.1650). Thomas- Maclean (2004) does contest whether it is ever possible for someone who has had breast cancer to return to 'normal' given the effects of treatment and suggests that 'reconstruction' might be a more appropriate term for the narrative that emerges after treatment.

The opportunity to return to normal never arose for those with FMS as there was no definitive treatment available. Throughout the study none of the participants described a return to their previous health status or the lives that they had lived previously. However, in a similar way to reconstruction described by those with breast cancer two of the participants in this study did attempt to redefine what good health and an ordinary life meant to them. At times there was an acceptance of the unpredictable nature of their illness, and it is possible that this narrative can return to the foreground when symptoms have negligible effects on the lives of patients and those around them. At this time a new concept of what it means to be 'well' and 'healthy' is negotiated, and 'normal' becomes redefined within the context of living with FMS.

It is suggested that "Perhaps restitution narratives are so powerful because they are most similar to what life might have been like if breast cancer had not intervened" (Thomas-Maclean, 2004 p.1651). This narrative encourages individuals with illness to look to the future when they will be better once more. Diagnosis with both HIV (Ezzy, 2000) and FMS causes individuals to be faced with an uncertain future yet the advances in the pharmaceutical management of HIV offers the possibility of treatment that is proven to minimise the symptoms of their illness. Restitution can therefore be a possibility unlike FMS.

The absence of definitive treatment to alleviate or resolve the symptoms of FMS did not stop participants within this study from attempting to seek them. Initially the restitution narrative was maintained by the hope that the prescription of medication and referral to others e.g. pain management programme, might provide the respite and recovery that was desired. In contrast to those with CFS (Whitehead, 2006) only a few of the study participants pursued complementary therapy or dietary changes when traditional remedies failed. Their appeared to be a high degree of scepticism regarding utilisation of alternative remedies in FMS: instead a quest narrative was adopted where there was withdrawal from aggravating activities or engagement with traditional management strategies such as pacing.

Many of those with HIV offered restitution narratives that acknowledged their lives might be shortened but continued to believe that they would continue as before, living to old age and able to achieve their previous goals (Ezzy, 2000). Planning for the future was a sub-plot within the restitution narrative of those with HIV (Ezzy, 2000) and reflected the belief that they had, or would, enact the outcome 'tomorrow I'll be better' (Frank, 1995). Their life story was intact and continued faith in the ability of medicine to devise new and better treatment for their condition reinforced this theme. Like those with breast cancer (Thomas-Maclean, 2004) it is possible that this is not a true restitution narrative as it is based on the premise of living a healthy life. In both instances it appears that the appearance of this narrative may be associated with a

denial of the illness they have and its effects together with negotiation of what it means to be well.

Threats to mortality were not an issue to those with FMS and whilst some of the participants were able to achieve, or consider achieving, previous goals these were primarily evidenced in the quest narratives where they could occur in the context of a new, modified life. That two participants with FMS frequently attempted to enact and return to the restitution narrative suggests that it might be possible to be considered healthy whilst still experiencing the effects of chronic disease provided these effects can be incorporated into a normal life story.

### **7.2.2 Chaos**

Within this study the chaos narrative initially emerged prior to diagnosis when symptoms they were experiencing failed to resolve, worsened or were unexpected. Its appearance was characterised by the increasing intrusion of FMS into their lives and the loss of control over their bodies and their lives. The time taken for this narrative to appear was influenced by the individual context within which the illness was experienced. The elusiveness of diagnosis, inability to get an adequate explanation and growing feelings of loss of credibility were symbolic of this period of their lives. Individuals had different thresholds for tolerating these factors and the time taken for chaos to emerge as a narrative preference was variable.

Similarly the time taken to restore the narrative of restitution was also varied but this was dependent on the condition of diagnosis. This event was determined by the time taken for individuals to seek a diagnosis as well as for referral to secondary care where diagnosis was made. During this period challenges to their identity were faced as doubts about their credibility (posed by themselves and others) arose. It is not possible from the results of this study to make claims to correlation between time to diagnosis and dominance of the chaos narrative in individuals with FMS. However, exploration could determine the role of early diagnosis in individuals with contested

and bio-medically invisible diagnoses. It is possible that this might support an earlier transition into a quest narrative and the opportunity to begin sooner the process of adjustment.

This expression of the chaos narrative symbolised by the battled to get diagnosed is also reported in the experiences of those with CFS (Travers and Lawler, 2008; Whitehead, 2006). They similarly often felt unsupported by their GP's leading to periods of "despair and vulnerability" (Whitehead, 2006) and shared the experience that symptoms did not follow a usual pattern. In both instances the invisible and unpredictable nature of the symptoms contributed to the chaos narrative and reinforced the syntactic nature of their symptoms as they recounted "and then, and then and then" (Frank, 1995).

Diagnosis in the study was not universally associated with the return of restitution or emergence of the quest narrative. Time mediated the meanings that were attached to the 'label' received and chaos once more emerged as participants comprehended the lack of credibility conferred. This was increased by the realisation that they were living with a condition that had an uncertain trajectory with no definitive treatment or prognosis. This finding was replicated in people with CFS (Whitehead, 2006; Travers and Lawler, 2008) and contributed to feelings attributed to the "violation of self" (Travers and Lawler, 2008 p318). Within the studies of breast cancer (Thomas-Maclean, 2004) and HIV (Ezzy, 2000) there was no report of stigma being associated with a chaos narrative suggesting that for contestable conditions it might be associated with lack of visibility through the biomedical lens.

Participants with FMS described challenges to their identity and perceptions of self. This was evidenced when they spoke of the stigma attached to the diagnosis, the frequency with which they felt their symptoms were trivialised or attributed to psychological causes, and the lack of visibility of the condition in society. Participants felt that health care professionals seemed aware of the condition but wanted to deny



it. FMS appeared invisible within the lay sphere of illness where, discussion of arthritis for example was common place yet, few people were aware of the condition known as FMS. FMS was only visible in other individuals who had the condition (who usually kept it hidden from those around them) and on internet web-sites that publicised the contested nature of the condition.

That diagnosis might be associated with stigma and challenges to identity had been considered on entering into the study following its identification in previous studies of patients with FMS (section 2.3.2 ). Further evidence to support the presence of this phenomenon has been identified (Cunningham and Jillings, 2006; Madden and Simm, 2006) and reinforces that people have little knowledge of FMS prior to diagnosis. In Norway it is possible there is increased awareness of FMS amongst the public: a number of individuals were aware of the stigmatizing nature of the diagnosis when it was received and this was accompanied by concerns regarding having a “women’s disorder” (Undeland and Malterud, 2007).

Whilst chaos in FMS is associated with time pre- and post diagnosis, for those with breast cancer (Thomas-Maclean, 2004) and HIV (Ezzy, 2000) this narrative emerged once diagnosis and the treatment that had to be entailed was considered. Whilst treatment and diagnosis offered the hope of restitution, there was also the threat to their mortality and chaos arose. Decisions had to be made about which treatment to start and the deleterious side effects of some treatments considered. For those with HIV there was less certainty surrounding the outcome of treatment and this contributed further to feelings of loss of control and false hope (Ezzy, 2000).

Chaos narratives in this study were also associated with participants being unable to come to terms with the losses that having FMS had brought about. This encompassed losses that had occurred at home, work and socialising. FMS was representative of the destruction of all that was good in their lives, including a desirable future. Movement out of chaos was impeded as time resulted in a cascade of additional

losses e.g. losing a job resulted in loss of income, and consequently less opportunity for socialising. This additionally impacted on their families and was witnessed in the developing breakdown of relationships and communication.

Losses associated with FMS have been described in other qualitative research studies (Crooks, 2007; Schoofs et al, 2004; Kelley and Clifford, 1997) further validating the findings from this study. These studies reported similar losses in: relationships, physical capabilities, employment, independence, quality of life and social support. None of this research was done in the UK and their samples were drawn from support groups or treatment programmes. The strength of these findings is improved by their presence in different health care communities suggesting loss is a manifestation of FMS in some individuals.

Other narratives of chronic illness using Frank's typology of chaos have demonstrated the deleterious impact on relationships and employment (Travers and Lawler, 2008; Ezzy, 2000). These individuals share the chaos narrative depicted by those with FMS where there is the loss of an idealised life and an inability to consider a future (where the known self was either diminished or lost). Participants in this study reported similar feelings of depression, anger, and fear (Whitehead, 2006; Travers and Lawler, 2008; Ezzy, 2000), although none of the other studies reported the presence of suicidal thoughts. Individuals with breast cancer (Thomas-Maclean, 2004) demonstrated chaos in relationships as a result of the psychological impact that a diagnosis of cancer caused and the loss of control over normal routines that families had to absorb. This was also true of those with FMS.

A loss of control is a dominant feature of the chaos narrative. For many of the participants with FMS the dominance of chaos was accompanied by stories of "living a life of overwhelming trouble and suffering" (Frank, 1995 p.113). Abuse, bereavement, children who were addicts and mental illness were described amongst this cohort. Whilst previously they had overcome these interruptions and stresses chaos had

returned and seemed to be a dominant feature of the life history that they were submerged in. This may add support to the evidence for stress being implicated in the aetiology of FMS (Pillow et al, 1996).

A loss of control may have been witnessed in the chaos narrative, of those with FMS, focussing on living in the present and taking one day at a time. However, the present itself was barren and failed to reflect that which had been planned for. The past had promised a different present and a future that they now denied. Their life story had been interrupted by FMS and this experience was shared in the chaos narratives of those with CFS (Travers and Lawler, 2008) and HIV (Ezzy, 2000). This was one outcome of living with uncertainty and stigma.

The inability to reconcile the past, present and future shows some alignment with the concept of biographical disruption described by Bury (1982): whilst almost thirty years old his qualitative interview study into the experiences of patients with rheumatoid arthritis was instrumental in gaining an insight into the impact of chronic illness. He suggested that chronic illness is an experience that disrupts life on a number of levels. Fundamental in its relevance to FMS is the notion that "the conditions which underpin most forms of disablement involve fluctuating symptoms and uncertain outcome" (Bury, 1982 p.168). Disruptions were considered to include: the disruptions of every day assumptions and boundaries; disruptions in explanatory systems used to make sense of a persons' life history and perception of self; and, disruption that warrants marshalling of resources. In contrast to FMS the diagnosis of rheumatoid arthritis is uncontested, and with current advances in its management and treatment this condition has greater certainty regarding prognosis. None the less, the findings of Bury's study (1982) still have some merit when attempting to understand the impact of chronic illness on individuals' lives, especially where there is an unknown trajectory.

Evidence that individuals within this study experienced biographical disruption is found in both the chaos and quest narratives. When the symptoms of this condition impinge

upon life individuals are unable to continue to live as previously. Initially attempts were made to absorb the impact of symptoms and the lack of satisfactory explanation or treatment. However, when this proved insufficient they were unable to maintain their roles and responsibilities in material, practical and relationship domains. This disrupted the assumptions and meanings upon which day to day life was founded. Diagnosis with a contested condition that had an uncertain illness trajectory increased the disruption. Chaos was symbolic of those individuals that were unable to reconcile the envisaged present and future with the reality being experienced.

Biographical disruption has been described previously in participants with FMS and CFS (Asbring, 2001) and highlights the discrepancies found in this study of how individuals are able or unable to renegotiate and restructure their lives. This differentiates between those that move to quest narratives or remain in chaos. Asbring (2001) further illuminates the biographical work that is done in creating new identities when individuals are experiencing chronic illness. Partial or complete identity transformation has been identified as a pre-requisite for individuals to be able to perform biographical work and come to terms with their altered life situation (Bury, 1982; Charmaz, 1983).

Individuals depicting chaos stories appeared to be characterised by an inability to come to terms with changes in their identity, or contingency of their bodies and their lives. Consistent with literature described in section 2.3.2 participants within this study described how the invisible, unpredictable and contested nature of their condition created feelings of stigmatisation. This combined with the losses they had experienced to create barriers to identity transformation. The result was stagnation and further chaos.

Stigma is described in the illness experience of many individuals with chronic illness (Scrambler, 1997). The social and cultural dimensions of this concept are described by Goffman (1963 p.2) in his classic work "Stigma": "Society establishes the means of

categorising persons and the complement of attributes felt to be ordinary and natural for members of each of these categories.... While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others... and of a less desirable kind—in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap”.

Cultural and societal judgements are made of what constitutes ‘ordinary’ and ‘natural’. Where individuals with FMS and other contested chronic illnesses describe chaos narratives it appears that stigma is associated with having an illness that is characterised by a lack of adherence to the ‘sick role’ (Parson’s, 1951) and/or failure to correspond to the biomedical model of health and illness. Those in chaos in this study were unable to transcend this negative perception of self and transform their identity in a manner they were able to come to terms with. They focussed on either their stigmatised identity or their pre-FMS identity and were unable to do the biographical work necessary for partial or complete identity transformation.

Chaos stories were characterised by their lack of cohesiveness and it is acknowledged that they can be difficult to hear (Frank, 1995). The absence of chaos stories in health care was described by those with breast cancer (Thomas-Maclean, 2008) and the potential benefits of listening to and telling these stories was considered by some participants, notably when they attended support groups. The lack of desire to hear chaos was evident in the participants of this study, who drew attention to friends, family and the health care professionals not being receptive to their tales of suffering. However, they themselves reinforced how hard it is to hear these stories: when considering going to the local support group they described how they did not want to bear witness to such narratives.

It would appear that independent of diagnosis there is a need for some forum to allow such narratives to be told and that denial of them discards the experience of those who are suffering. It is possible that making public accounts of chaos might allow acceptance of this narrative as a normal narrative in certain circumstances e.g. when diagnosed with cancer or a chronic illness. Without an opportunity to be heard it is possible that healing may be denied: if health care is to embrace the holistic care of patients it must open itself to listening to these stories.

### **7.2.3 Quest**

Some participants (n=6) were unable to transcend the biographical disruption and threat to identity that FMS had caused, and continued to tell stories where chaos perpetuated. For the remainder quest emerged as a narrative after participants had been diagnosed and with the realisation that cure was not possible. The time taken for this to take place was variable and dependent on the ability to overcome the biographical disruption caused by FMS. This study has proposed the presence of two quest plot-lines, active engaging and active disengaging, and will this section will highlight how the biographical re-writing that occurs in quest might not always be deemed a positive outcome in health care.

Bury's (1982) description of biographical disruption raises the awareness of how pain and discomfort (in this instance in rheumatoid arthritis) raises awareness of the body and its contingency, and in doing so disrupts the boundaries and assumptions within which individuals exist. This was observed in the participants in this study and those that adopted quest narratives were characterised by their ability to accept and integrate the contingency of their body. This was performed in two ways: they either accepted the invisible and unpredictable nature of their symptoms recreating a new 'normal' and/or adopted strategies that minimised the effects that the symptoms had on their bodies and lives. This was impacted upon by the decision to either actively engage or disengage: these sub-plots of the quest narrative were defined by the belief

that if they were to live once more in an acceptable present, and regain sight of an amenable future, then change would be needed.

Quest as a dominant narrative is also identified in CFS (Travers and Lawler, 2008; Whitehead, 2006; Reynolds and Vivat, 2006). It is less evident in breast cancer (Thomas-Maclean, 2004) and may be explained in part by the possibility of 'cure' or 'reconstruction'. Polyphonic narratives are described in HIV (Ezzy, 2000) as one narrative: life is orientated towards the present, which is embraced, and whilst the future is considered plans are avoided. This narrative is defined by the embracing of contradictions in goals, values and attitudes that I would suggest reflects 'quest' defined by Frank (1995) through the implication that 'life will never be the same again'.

Living life differently, changing jobs, reorganising schedules and pacing were dominant themes in those with CFS (Travers and Lawler, 2008, Whitehead, 2006; Reynolds and Vivat, 2006) and this reflects the findings of this study in FMS. Travers and Lawler (2008 p.322) described this as a "Reconstructing Response" whose "primary purpose was to redefine and renew positive experiences of self, construct meaning and improve quality of life". This once more mirrors the biographical work described by Bury (1982) undertaken by those with chronic illness and emulates the narratives of the participants describing quest within this thesis.

Both types of the quest narrative proposed within this study were influenced by the fact that with FMS routines and roles can no longer be fulfilled and the mobilisation of resources and social networks is required if the disruption is to be overcome (Bury, 1982). They both sought financial resources such as DLA: those disengaging would use it to support staying at home and employing others e.g. a cleaner to perform tasks for them, in contrast to those engaging that used the same resources to support them in a return to work e.g. paying for transport. Both groups often relied on other people to help them do things differently: for example, the active engagers would have extra support from family at home, so they could go back to work whilst the

active dis-engagers would have extra support at home as means of managing symptoms but not doing any more. Over time those disengaging found it increasingly difficult to maintain the levels of support and became increasingly socially isolated; occasionally this returned them back to chaos.

These findings are also consistently found in recent studies (Lunberg et al, 2007; Cunningham and Jillings, 2006; Schaefer, 2005) that explore the illness experience of FMS. They describe the ability of some patients to regain control over their lives, albeit living a life that now looks different or is enacted differently. As with the participants in this study it has been suggested that those who are able to survive the experience of moving with pain (Lunberg et al, 2007; Cunningham and Jillings, 2006; Schaefer, 2005) accept their changed life situation and adopt both physical and psychological coping mechanisms.

The participants within this thesis are, with the exception of 1, female. In contrast with other study findings that predominantly investigate women's experiences, a study of men with FMS (Paulson, Danielson and Soderberg, 2002) suggested that living with FMS 'successfully' was the product of trying to make the illness invisible and attempting to live as normally as possible. It is not possible from this thesis to make any inferences regarding gender differences but the resuming of life whilst evident in some quest stories was absent from others.

The ability to accept that life would never be the same again has been shown to be a dominant feature of the quest narrative described by the participants of this study. In overcoming the biographical disruption caused by the onset of illness and the diagnosis it is apparent that the participants had to renegotiate their identity and perceptions of self. This reflects the findings Kathy Charmaz (1983) who identified, through interviews with individuals experiencing a variety of chronic illnesses, the "loss of self" that occurs. Whilst the individuals in her study were frequently housebound



and did not exclusively have musculoskeletal conditions her findings are transferable to this study.

The "loss of self" described by Charmaz (1983) epitomised the experience of individuals with chronic illness who witnessed "their former self-images crumbling away without a simultaneous development of equally valued new ones" (Charmaz, 1983 p.168). Her conceptual model emphasised the narrow view of medicine exposing the physical aspects of disease and suffering whilst paying little attention to the psychological. Within this study those participants who were able to tell quest narratives were able to come to terms with their initial 'loss of self' and perform biographical work that allowed them to visualise and create both new lives and identities.

The quest narrative in this study became synonymous with different types of identity transformation taking place. Partial identity transformation took place with some participants in the active engaging attempting to continue with previous roles and obligations albeit with modifications e.g. flexible working, or extra support. Others recreated a new identity and this appeared to take two main formats. A few remaining within the active engaging group decided to use the opportunity to consider new lives such as a new job, or retiring. The active disengaging group adopted the permanent 'sick role' withdrawing from societal obligations and seeking help and assistance wherever possible. This challenges the concept that quest is a functional enabling narrative (Travers and Lawler, 2008; Whitehead, 2006; Reynolds and Vivat, 2006; Thomas-Maclean, 2004; Frank, 1995). For some individuals quest can be indicative of a story of dysfunction and dependence, where control has been restored through the relinquishing of roles and responsibilities.

Identity transformation has been described in 3 Swedish studies (Lundberg et al, 2007; Paulson, Danielson and Soderberg, 2002; Asbring, 2001). These studies highlighted how coming to terms with living with FMS was associated with restoring or

transforming their identities. Like the individuals in this study this could not take place until they had acknowledged the identity that they had lost. Similarly the process was associated with a re-evaluation of what they considered to be 'quality of life'.

Reflecting the participants with FMS in this study, these authors reported (Asbring, 2001; Lundberg et al, 2007) how this process required an acceptance of their symptoms, reorganization and a reconsideration of what was an acceptable life.

Other studies utilising Franks' narratives have also identified the biographical work taking place within the quest narrative. The reconstructing response (Travers and Lawler, 2008) was characterised by individuals with CFS recreating positive self perceptions whilst art-work was considered to play a role in reconnecting with personal and family history, restoring an identity where individuals perceived themselves as useful again (Reynolds and Vivat, 2006). Identity transformation was less common in individuals with breast cancer (Thomas-Maclean, 2004) perhaps reflecting the dearth of quest stories and that many of the women were able to return to their previous lives, and continue to do things in the same way.

From this discussion it is possible to see how the quest narrative is a story of transformation and in its broadest terms 'survival'. Participants, in this study with FMS, described narratives that evidenced how they had experienced the onslaught of FMS, the battle to be diagnosed and its strengths and limitations, and evolved to be the individuals that they are now. These are individuals who for the most part have regained control over their bodies and lives, albeit sometimes at odds with the conception health care typically has of what constitutes successfully coping.

### **7.3 Clinical relevance**

The findings of this study suggest that whilst individuals with FMS demonstrate heterogeneity within their unique stories, unifying plots are discernible and are indicative of how they are interpreting and making sense of their illness experience. It is hoped that the identification of the three narrative typologies will combine with the description of the underlying themes presented in this thesis to assist clinicians in

understanding the illness experience of FMS. In recognising how individuals are interpreting their illness experience it is possible that assessment and management strategies can become more patient centred.

The findings of this study suggest that early diagnosis of FMS may be important in reducing the time that patients with FMS spend in chaos pre-diagnosis. Diagnosis has the potential to reduce the biographical disruption and changes to identity that occurs its' absence. Labelling symbolises the opportunity for patients to begin the biographical work needed to adjust to living with FMS. Once provided patients can begin this process both independently and with support from health care staff.

I would suggest that the active enabling model of quest is indicative of a narrative where health care professionals can engage with patients to establish patient centred goals that can be achieved through provision of appropriate advice and access to resources. For some patients this might suffice and enable them to do the biographical work that is necessary. Others might warrant further support or intervention e.g. attendance at a pain management programme or physiotherapy. Those in chaos may require greater attendance to addressing the psychological and social aspects of their illness and lives. Many of these individuals appear to want to escape the suffering of their lives, but will need support to make these changes and to engage with health care services. It is my opinion that those who actively disengage present the greatest challenge to health care. Their goals of withdrawing are likely to be at odds with health care and providers of benefits as they appear to be content with their new biography.

Recognising the presence of these narratives will require greater attendance to the accounts that patients give. It raises the importance of listening to all stories, including those of chaos that can be difficult to engage with. This may require a paradigm shift in health care provision for these patients: less emphasis should be placed on the identification of causation and administration of treatment, and greater emphasis on listening to the physical, psychological and social impact of their illness experience.

#### **7.4 Recommendations for further research**

Whilst achieving its aim of describing the lived experience of individuals with FMS this study has also raised further questions and opportunities for research. My recommendations for future research include:

- Replication of this study in (a) other Secondary Care Settings and (b) Primary Care to ascertain whether the findings were unique to this setting
- Investigation of the illness experience of non-patients with FMS i.e. those with symptoms and no diagnosis.
- Further attempts to explore the illness experience of men with FMS to identify whether illness narratives in FMS are influenced by gender
- Observation studies to investigate communication between patients with FMS and health care practitioners: are narratives visible in these encounters?
- Mixed methods studies to investigate whether identification of illness narratives (and therefore sub-classification of patients with FMS) affects prognosis

#### **7.5 Conclusion**

This chapter has interpreted the results of this research study in the context of other research that has used Frank's (1995) narrative typologies or explored the illness experience of FMS. In doing so it has provided evidence of how the research question has been answered and the aims of the study met. It has supported the presence of the three narratives of quest, chaos and restitution and provides further evidence for the robustness of this model in chronic illness. It has highlighted that the development of an explanatory model, such as this, could be used by clinicians to reflect upon and better understand the stories that are told. With recognition of these narrative types it might be possible to better listen to the illness experience of the individual, improve engagement with them and implement holistic management that best meets their needs.

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## APPENDIX 1

### **The American College of Rheumatology Classification Criteria (Wolfe et al, 1990)**

#### **1. History of widespread pain for at least 3 months**

##### *Definition*

Pain is considered when all of the following are present:

- Pain in both sides of the body
- Pain above and below the waist
- Axial skeleton pain (cervical spine or anterior chest or thoracic spine or low back)

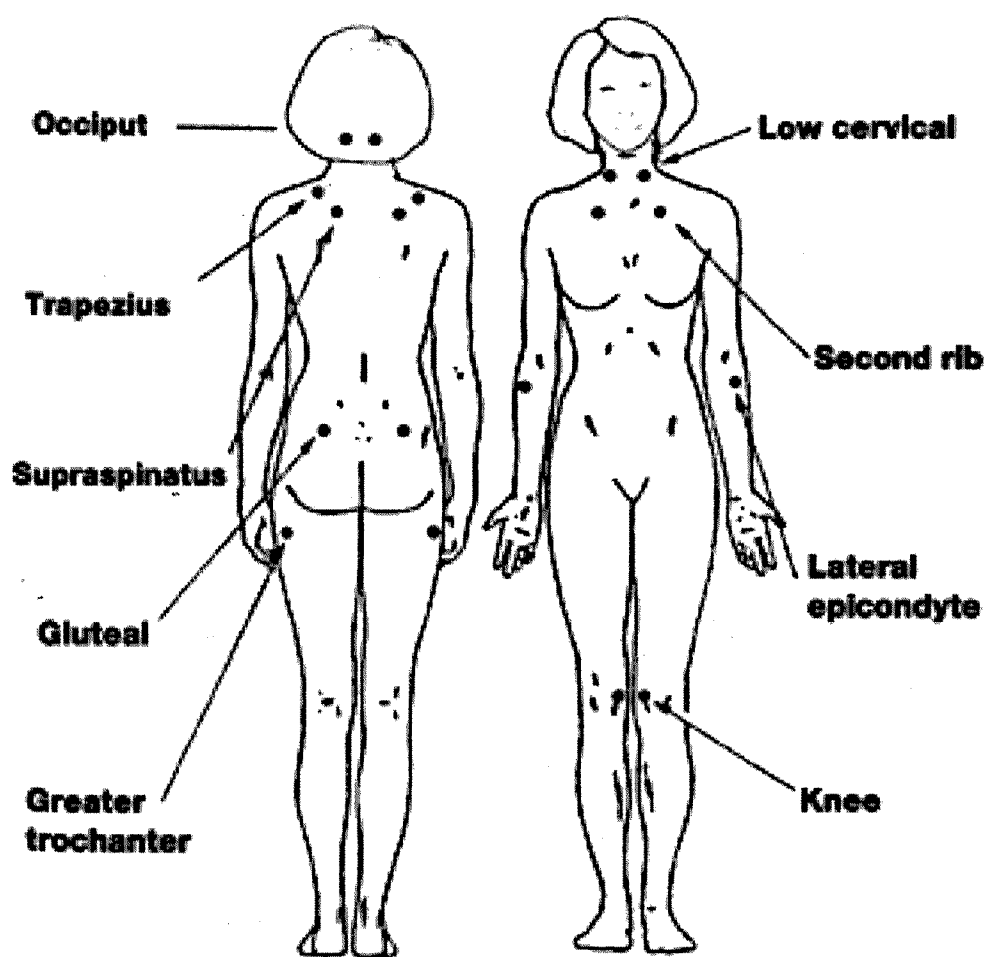
Shoulder and buttock pain are considered as pain for each involved side. Low back pain is considered lower segment pain.

**2. Pain in at least 11 of 18 tender-point sites on digital palpation which should be performed with an appropriate force of 4kgf. For a tender point to be considered positive, the patient must state that the palpation was 'painful'; a reply of 'tender' is not to be considered painful.**

##### *Definition*

- Occiput: Bilateral at suboccipital muscle insertions
- Lower cervical: Bilateral, at anterior aspects of the intertransverse spaces at C5-C7
- Supraspinatus: Bilateral, at second costochondral junctions, just lateral to junctions on upper surfaces
- Lateral epicondyle: Bilateral, 2cm distal to epicondyles
- Gluteal: Bilateral, in upper outer quadrants of the buttocks in anterior fold of muscle
- Greater trochanter: Bilateral, posterior to trochanteric prominence
- Knees: Bilateral, at medial fat pad proximal to joint line

Sites of the 18 fibromyalgia tender points as defined by the ACR criteria (Wolfe et al, 1990)





## APPENDIX 2

### Ethical approval documentation

Trent Health Authority

Please ask for:  
Linda Ellis, Administrative Assistant  
Ext: 49435 E-mail: [linda.ellis@trenthsa.nhs.uk](mailto:linda.ellis@trenthsa.nhs.uk)

Nottingham Research Ethics Committee  
1 Standard Court  
Park Road  
Nottingham  
NG1 2RN

Tel: 0115 912 3044  
Fax: 0115 912 3045

Our Ref: C2100208

27<sup>th</sup> November 2002

Mrs C J Diver  
Department of Physiotherapy  
Division of Physiotherapy Education  
NCH

Dear Mrs Diver

Re: The perceptions, experiences and expectations of treatment in fibromyalgia syndrome

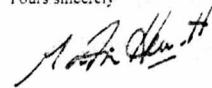
Thank you for submitting the above project for consideration by the Ethics Committee. The Ethics Committee met on 25<sup>th</sup> November 2002 and is happy to approve the project subject to clarification and amendments as set out below:

- Where will the tapes be stored and reassurance that they will be destroyed at the end of the study? ✓
- You have not signed as the lead investigator on the application form ✓
- Clarification as why these particular patients have been chosen ✓
- The supervisors name should be included ✓
- There should be provision of an invitation letter ✓
- The Committee cannot approve phase II of the study, this will have to be re-submitted at a latter date ✓

On receipt of this information and it being considered satisfactory a full approval will be forwarded to you.

Kind regards

Yours sincerely



Dr M Hewitt  
Chairman  
Nottingham Research Ethics Committee 2

Nottinghamshire Primary Care Services  
Run through Rushcliffe Primary Care Trust and also working for the following  
Primary Care Trusts - Broxtowe and Hucknall, Gedling and Nottingham City

## Trent Health Authority

Administrative Assistant  
E-mail: [admin@trent-ha.nhs.uk](mailto:admin@trent-ha.nhs.uk)

Nottingham Research Ethics Committee 1  
Standard Court  
Park Road  
Nottingham  
NG1 6GN

Tel: 0115 912 3344  
Fax: 0115 912 3300

REC C2100208

(please quote this number on all correspondence)

10 April 2003

Mrs Claire Diver  
Physiotherapy Lecturer Practitioner  
Nottingham City Hospital  
Hucknall Road  
Nottingham  
NG5 1PB

Dear Mrs Diver

Re: **The perceptions, experiences and expectations of treatment in fibromyalgia syndrome**

The Chair of the Nottingham Research Ethics Committee 2 has considered the amendments submitted in response to the Committee's earlier review of your application on 25 November 2002 as set out in our letter dated 27 November 2002. The documents considered were as follows:

- . Application Form
- . Protocol
- . Patient Information Sheet
- . Consent Form
- . Letter of Invitation

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study. On behalf of the Committee I am, therefore, happy, to give full approval for this study on the understanding that you will follow the conditions set out below:

1. The Project must be started within three years of the date on which REC approval is given.
2. You must not start your project in any institution until you have received written approval from their R&D department. You should have submitted your original application to the R&D office and parallel reviews will have been taking place. Approval should therefore be imminent.

Nottinghamshire Primary Care Services  
Run through Rushcliffe Primary Care Trust and also working for the following  
Primary Care Trusts - Broxtowe and Hucknall, Gedling and Nottingham City

Page 1 of 2

If your study is to take place in any of the following units then you do not need further ethical approval but you do need R&D approval.

- Queen's Medical Centre
- Nottingham City Hospital
- Nottingham Primary Care Trusts
- Mental Health Care Trust

If your study is to take place in units outside of Nottingham but still within the boundaries of the Strategic Health Authority, then you do not need further full ethical approval. You will however need your study approved by the R&D unit of the institution concerned and an assessment of 'locality issues.' These 'locality issues' (such as appropriate status of research aspects of local research subjects, information sheets) are usually addressed and reviewed by the local ethical committee and you should clarify this point with the administrator of your local REC. These reviews should take place quickly.

3. You must not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate immediate hazards to research participants or when change involves only logistical or administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.
4. You complete and return the standard progress report form to the REC one-year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.
5. If you decide to terminate this research prematurely you send a report to this REC within 15 days, indicating the reason for the early termination.
6. You advise the REC of any unusual or unsuspected results that raise questions about the safety of the research.

Yours sincerely

Dr M Hewitt/Mrs L Ellis  
Chair/Administrator  
**Nottingham Research Ethics Committee 2**

cc Research and Development

Please ask for:  
Linda Ellis Administrative Assistant  
Ext: 49435. E-mail: linda.ellis@rushcliffe-pc.nhs.uk

Nottingham Research Ethics Committee 2  
1 Standard Court  
Park Row  
Nottingham  
NG1 6GN

Tel: 0115 912 3344  
Fax: 0115 912 3300

REC C2100208

(please quote this number on all correspondence)

5<sup>th</sup> October 2003

Mr G D Pope  
Head of Division  
School of Community Health Sciences  
Division of Physiotherapy  
Clinical Sciences Building  
NCH

Dear Mr Pope

Re: The perceptions, experiences and expectations of treatment in fibromyalgia syndrome

Thank you for your letter dated 29<sup>th</sup> July 2003 informing us of the following changes:

- Addition of 2 further periods of data collection

Under delegated authority I can give this amendment Chairman's approval subject to submission of the following information and/or amendments, which are detailed below:

- New Information sheet to include new interview times

Yours sincerely

Dr M Hewitt/Mrs L Ellis  
Chair/Administrator  
Nottingham Research Ethics Committee 2



REC reference number: C2100208 Please quote this number on all correspondence

Ms C Diver  
Physiotherapy Lecturer/Development Manager  
Physiotherapy Department  
NCH

2<sup>nd</sup> June 2004

Dear Ms Diver

**Full title of study:** The perceptions, experiences and expectations of treatment in fibromyalgia syndrome  
**REC reference number:** C2100208  
**Protocol number:** N/A

**Amendment number:** N/A  
**Amendment date:** 14<sup>th</sup> April 2004

The above protocol amendment was reviewed by the Sub-Committee of the Nottingham Local Research Ethics Committee at the meeting held on 24<sup>th</sup> May 2004.

#### **Ethical opinion**

The members of the Committee present gave ethical approval for the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Invitation Letter  
Patient Information Sheet  
Consent Form

#### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

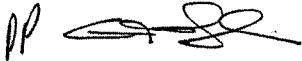
#### **Management approval**

Before implementing the amendment, you should check with the host organisation whether it affects their approval of the research.

**Statement of compliance (from 1 May 2004)**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees in the UK (2004) and complies fully with national standard operating procedures.

Yours sincerely,



**Mrs L Ellis**  
**Committee Administrator**

Cc Sponsor

Enclosures *List of names and professions of members who were present at the meeting  
or who submitted written comments*

An advisory committee to Trent Strategic Health Authority

### APPENDIX 3

Claire Diver  
Physiotherapy Lecturer/Practitioner  
Division of Physiotherapy Education  
Clinical Sciences Building  
Nottingham City Hospital Campus  
Hucknall Road  
Nottingham  
NG5 1PB  
0115 9691169 ext 46679/34880

Dear

**Re: The experiences of patients with fibromyalgia syndrome**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. To help you make this decision I have enclosed an information sheet. Please take time to read the information carefully and discuss it with others, if you wish.

If you have any questions or would like more information please contact me on 0115- 9691169 ext. 46679/34880. Take time to decide whether or not you wish to take part. If you do not take part it will not affect the standard of care that you will receive.

If you would like to take part please complete the enclosed consent form, and return it in the pre-paid envelope supplied. If you do not want to take part you do not have to do anything further.

With thanks for you time.

Yours sincerely

Claire Diver MCSP

Physiotherapy Lecturer/Practitioner  
Rheumatology

Dr Adrian Jones

Clinical Director

Enclosures (2)

## APPENDIX 4

### PATIENT CONSENT FORM

**Title of project** The perceptions, experiences and expectations of treatment in fibromyalgia syndrome.

**Site** Nottingham City Hospital

**Investigators** Claire Diver

You should complete this form yourself.

**Please cross out as necessary**

- Have you read & understood the patient information sheet YES/NO
- Have you had opportunity to ask questions & discuss the study YES/NO
- Have all the questions been answered satisfactorily YES/NO
- Have you received enough information about the study YES/NO
- Who have you spoken to  
Dr/Mrs/Ms .....
- Do you understand that you are free to withdraw from the study
  - at any time YES/NO
  - without having to give a reason YES/NO
  - without affecting your future medical care YES/NO
- Do you agree to take part in the study YES/NO
- Do you understand that you may not be offered any additional treatment after the study has finished YES/NO

Signature (Patient)

Date

Name (In block capitals)

I have explained the study to the above patient and he/she has indicated his/her willingness to take part.

Signature (Physiotherapist)

Date

Name (In block capitals)



## APPENDIX 5

### **Patient invitation letter: The perceptions and experiences of patients with fibromyalgia syndrome**

Claire Diver  
Physiotherapy Lecturer/Practitioner  
Division of Physiotherapy Education  
Clinical Sciences Building  
Nottingham City Hospital Campus  
Hucknall Road  
Nottingham  
NG5 1PB  
0115 9691169 ext 46679/34880

Dear

#### **Re: The perceptions and experiences of patients with fibromyalgia syndrome**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. To help you make this decision I have enclosed an information sheet. Please take time to read the information carefully and discuss it with others, if you wish.

If you have any questions or would like more information please contact me on 0115- 9691169 ext. 46679/34880. Take time to decide whether or not you wish to take part. If you do not take part it will not affect the standard of care that you will receive.

If you would like to take part please complete the enclosed consent form, and return it in the pre-paid envelope supplied. If you do not want to take part you do not have to do anything further.

With thanks for you time.

Yours sincerely

Claire Diver MCSP

Physiotherapy Lecturer/Practitioner

Enclosures (2)

**Patient information sheet: The perceptions, experiences and expectations of treatment in fibromyalgia syndrome** Claire Diver MCSP

**Introduction**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

*If you choose to take part you will be given this information sheet and a copy of your signed consent form to keep.*

Thank you for reading this.

**What is the purpose of this study?**

We want to improve the service that we currently provide to patients with fibromyalgia. In order to do this, we want to find out what you understand about your condition, how it affects your life, what treatment you might have had (and what you thought about it), and what treatment you think would help.

**Why have I been chosen?**

We have chosen your name from the Rheumatology Department's records of people who have attended the clinic with a diagnosis of fibromyalgia in the last 12 months.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will happen if I take part?**

You will be invited to come to the Nottingham City Hospital for an interview with the main researcher. This will last approximately one hour and you will be asked to talk about your experiences of fibromyalgia. This interview will be audio-taped.

**What are the possible benefits of taking part?**

This information will enable us to get a better understanding of the experiences of patients with fibromyalgia. It is hoped that we will be able to use this information in the management of patients with fibromyalgia.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it.

**What will happen to the results of the research study?**

We may use the information when planning future services for patients with fibromyalgia. The findings will also be written up and submitted for publication. You would not be identified in any report or publication.

**Who is organising and funding the research?**

It is being organised by the University of Nottingham and Nottingham City Hospital.

The study is being funded by the Physiotherapy research Foundation.

**Contact for further information**

Claire Diver

Physiotherapy Lecturer/Practitioner

Division of Physiotherapy Education

Clinical Sciences Building

Nottingham City Hospital Campus

Hucknall Road

Nottingham

NG5 1PB

Tel: 0115 8404886/8404880

**Should you choose to take part in this study you will be given a copy of this information sheet and a signed consent form to keep.**

## APPENDIX 7

### INTERVIEW GUIDE 1

#### **Introductory explanation**

Introduce myself.

Describe interview process, study, how information will be used.

Highlight that this study is NOT part of any treatment programme and that they will NOT be offered any treatment as a result of issues that arise in the study.

#### **Demographic information and disease factors**

Age, gender, marital status, socioeconomic status, comorbid conditions, symptom duration, disease duration

#### **Perception of FMS**

What does the pain mean to them? "Tell me about the pain that you get".

##### *Prompts*

- Describe the pain that you experience.
- How does the pain make you feel?
- How does the pain affect you/your life?

What does the fatigue mean to them? "Tell me about the fatigue/tiredness that you feel"

##### *Prompts*

- Describe the fatigue/tiredness that you experience.
- How does the fatigue/tiredness make you feel?
- How does the fatigue/affect you/your life?

What does the diagnosis mean to them? "Tell me how you felt when you were diagnosed with fibromyalgia"

##### *Prompts*

- How did they feel before they got the diagnosis of FMS?
- Did they have to struggle to get to see a Consultant?
- What do they understand by the diagnosis?
- Was the diagnosis/prognosis explained to them?
- What information did they receive about fibromyalgia? Was this enough? Did they get the chance to ask questions?

#### **Self-perception**

How do they perceive themselves? "How does having fibromyalgia affect the way you feel about yourself?" "How has having fibromyalgia affected how others are with you/see you?"

### *Prompts*

- How is your relationship with your husband/children/significant others/friends/work colleagues?
- Do you think having fibromyalgia affects how other people (husband/child/friend/Dr etc) are with you?
- What do other people think about your illness when you look well/they can't see anything physical wrong with you?
- Do you have any problems with believing that you are ill?
- How do you see your future?

### **Quality of Life**

What impact has fibromyalgia had on their quality of life. "How has fibromyalgia affected your life?"

### *Prompts*

- What was your life like before you had fibromyalgia? What is it like now?
- What can't you do now that you could do before you had fibromyalgia?
- Have you gained anything from having fibromyalgia?
- Does having fibromyalgia affect how you live on a day to day basis?
- Are you able to plan for the future?

### **Coping strategies**

What strategies do patients with fibromyalgia use to cope with their illness? "What do you do to cope?"

### *Prompts*

- How do you cope day to day? In the long-term?
- Have you had any treatment for your fibromyalgia? What? Was it helpful? Were you sent? Did you send yourself/find out about it yourself?
- What have you found helpful/unhelpful in managing the pain/fatigue/symptoms of fibromyalgia? Why?
- Have you used any of the self-help groups/literature? Which? How did you get the information? Did you find it useful? Why?

### **Closure of interview**

Thanks for time and information they have given. Reiterate confidential nature of the interview.

Is there anything more that you think it is important to tell me about your experience of living with fibromyalgia.

Advise will be in touch in the next 12 months to interview them, and remind them that they can withdraw from the study at any time.

## APPENDIX 8

### INTERVIEW GUIDE 2

#### **Introduction**

Welcome and thanks for coming back

Clarification of the interview and research process

#### **How have things been in the last year/since we last met?**

*Prompts might include*

- Recap their symptoms to them. How have your symptoms been? The pain? The fatigue? Any other symptoms specific to the patient?
- Can you tell me about any treatment you've undertaken in the last year?
- What were you hoping for before you went?
- How did you find it?
- Have you had to go back to your GP/Consultant? How has that been?
- When we last spoke you mentioned that you coped by 'x'. Have you found any other ways of coping since then?
- When we last spoke you described how it was affecting your relationships with (a) family and (b) friends? How have things been since then?
- At our last meeting we discussed how you had given up/remained in work? Have things changed in the last year and how?
- When we last met you described how the fibromyalgia was affecting you being able to plan for the future? Do you feel you can plan any better for the future now?
- At the first interview you mentioned how the fibromyalgia had/had not affected how you felt about yourself. Has this changed in the last year?
- Discuss any things else specific raised by that particular patient.
- Ask if they have any thing else they would like to add that has not been discussed.

#### **Closure of interview.**

Thank them for their participation. Ask if they would like a copy of the transcript and if they would be happy to be contacted in another

### RR-PL-869 - Research Report Abstract

THE PERCEPTIONS AND EXPERIENCES OF PATIENTS RECENTLY DIAGNOSED WITH FIBROMYALGIA SYNDROME.. Claire Diver<sup>1,2</sup>, Mark Avis<sup>1</sup>, Kaye Freeman<sup>1</sup>; <sup>1</sup>The University of Nottingham, Nottingham, UK; <sup>2</sup>Nottingham University Hospitals NHS Trust, Nottingham, UK

**PURPOSE:** To describe the perceptions and experiences of patients on being recently being diagnosed with fibromyalgia syndrome. **RELEVANCE:** Fibromyalgia syndrome (FMS) is a musculoskeletal condition of unknown aetiology characterised by chronic widespread pain and poor sleep. It predominantly affects middle-aged women. There is no diagnostic test and diagnosis is criteria based and often contested. Previous studies have reported patient perceptions of being diagnosed with fibromyalgia but this is in patients who have been in receipt of their diagnosis for some time (1-30 years). This study investigates this phenomenon within 2 months of diagnosis. **PARTICIPANTS:** 23 patients (22 female, 1 male) with a first diagnosis of FMS by a Consultant Rheumatologist were recruited from a Secondary Care Hospital. The patients are part of a larger longitudinal and on-going 2 year study. **METHODS:** Qualitative in-depth semi-structured interviews were used to identify the perceptions and experiences of patients recently diagnosed with FMS. An interview guide was formulated from previous research on FMS and chronic illness. Patients were given of choice of where the interview was conducted: their home, the hospital, the university or any other venue they suggested. The Fibromyalgia Impact Questionnaire (FIQ) was performed at baseline to describe the sample recruited. Interviews were tape recorded and hand written notes made. **ANALYSIS:** The interviews were transcribed verbatim. They were analysed using qualitative content analysis. The data was coded using NVivo and then recurrent themes and meanings were identified. **RESULTS:** 'Being diagnosed' was an important event in the patient's life. Four descriptive categories were grounded in the data, labelled struggle for a diagnosis, meanings attached to the diagnosis, access to help and the future. For many patients the receipt of a diagnosis was a significant event in a journey that had usually begun some years previously with a visit to their GP. Whilst the diagnostic label legitimised the way they felt, it was also interpreted as 'uncertain' and 'incurable' and frequently linked with previous life events. Provision of a diagnosis provided them access to help and information that was previously unavailable and for some to consider the future and begin the process of acceptance and adaptation. **CONCLUSIONS:** This study highlights the importance of receiving a diagnosis to patients with an 'invisible illness' like FMS and the importance of validating both subjective and objective findings. There are disadvantages of diagnosis associated with stigma and an uncertain illness trajectory. However, these are outweighed by the advantages of being able to construct a new identity, acknowledgement and acceptance of the illness and the ability to consider adaptive coping strategies.

**IMPLICATIONS:** Currently there is a predominance of the "biological" in the biopsychosocial model, in the assessment and management of patients with FMS. Health care professionals should be made aware of the importance of an early diagnosis on the perceptions and experiences of patients with FMS. In assessing and managing patients with FMS they need to consider: the importance of being believed; the role of a medical diagnosis; the significance of the language used and the impact of diagnosis on identity and stigma. **KEYWORDS:**  
Qualitative research  
Semi-structured interviews  
Fibromyalgia syndrome (FMS)  
Diagnosis

**FUNDING ACKNOWLEDGEMENTS:** None **CONTACT:** claire.diver@nottingham.ac.uk

### VIGNETTES OF ILLNESS NARRATIVES

The truncated vignettes presented are intended to provide illustrations of narratives of individuals that have FMS and to highlight some of the key themes (previously described in detail in the results section). They are intended to serve as a guide for clinicians to aid further understanding of the narratives of quest, chaos and restitution presented in the main thesis.

#### **Restitution**

In the restitution dominant narrative there is witnessed a strong desire for resolution that given the chronic nature of FMS and the biographical disruption caused is unlikely. With advances in knowledge of aetiology and management continued attempts will be made to enact this. This narrative is evident in all individuals when their symptoms first occur and for some returns when diagnosis is made. It remains as a background narrative for most with the hope that one day it will be possible.

#### ***The narrative of participant 15***

Participant 15 was a white female who was 37 years of age on entry into the study. She was working in an administrative role and was living with her husband. She had 3 children living at home, none of whom were of school age. She had previously had problems with low back pain, and couldn't remember for how long, but had become used to self managing this.

She reported having symptoms for 3 years prior to receiving her diagnosis. The symptoms that initially occurred were a combination of widespread pain and tiredness, and were considered to be the usual complaints of being a working mum. When they had first begun two of her children were still at school. Her husband worked in a job that sometimes entailed him being away from home. P15 would describe how she was always busy and that this was a product of home and work life but also additional activities she would engage in including charity fund raising work and helping friend with their child care needs. This provided her with a rational explanation for her symptoms: they were the result of "overdoing things" and this described in her first interview:

"At first I just thought it was because I'd been doing so much. They say 'if you want something doing ask a busy person' and that was me. There were the kids, work and then helping out friends. And then there was the charity work, fundraising, and once



going out to see the school we'd raised money for. It wasn't surprising that I was tired and ached was it" Participant 15

At first she didn't change anything in her lifestyle: she tolerated the symptoms and accepted that whilst she continued to be as busy they would be unlikely to resolve. She was able to remember a time previously when she hadn't been as busy and when she felt fine. When her symptoms began to worsen she decided to reduce some of the demands upon her time: she advised friends she couldn't help them with childcare, did less housework and reduced her involvement with charity work. This made little difference to her symptoms and she thought that this was because she had not persevered with it long enough. Resolution failed to materialise and she tried taking painkillers and multi-vitamins.

Eventually she took time off work unable to cope with the daily travel in (she had resorted to taking taxis as she couldn't cope with the physical strain of taking the bus) and demands of her job. She returned after a week but realised she was no better and went to see her GP hopeful that they could explain what was wrong and provide advice or treatment that would help her to get better:

"And well at this point you've tried everything that you know you should, and that you know should work. Normally if you're tired and your backs aching you slow things down, rest, take some tablets and you're sorted. But things just got worse. So when you can't help yourself anymore you go to your GP, and hope that they can help- tell you what's wrong and what to do to make it better. But they didn't seem to know either and you try everything they tell you but still no joy. So then you wonder what's wrong and want to see someone else, get to the bottom of it" Participant 15

After a few months of being off work and reducing her activities at home she was no better: describing a lack of confidence in her GP she then asked for a referral to the hospital.

P15 anticipated that being seen by a 'specialist' at the hospital would allow her access to tests and medical expertise that would be able to provide an explanation for what was wrong with her. In addition it would allow access to treatment and resolution of her condition. Being diagnosed was important to provide a label and help understand the nature of her complaints. She adopted the advice that she was given regarding management of FMS, pacing herself and taking her medication regularly.

"You know since then I've just kept doing what they told me. Pacing, the amitriptylline, not over-doing things. And I go to the support groups and look on the internet. You

never know one day it might eventually go if I keep doing this or if a treatment comes on the market I'll be able to take it" Participant 11

The desire to enact restitution never disappeared. She remained optimistic that adherence to suggested management strategies would one day be successful.

### **Quest dominant (active engagement)**

Quest (active engagement) is witnessed as a dominant narrative when there is a strong desire to minimise the effects of FMS with a return to some semblance of a previous life or emergence of a new life. Partial or complete identity transformation is performed as part of biographical work to come to terms with their new life situation. Examples are evident of strategies adopted to actively engage with treatment and the multitude dimensions of their lives. Social support is frequently evident at home and/or via other networks e.g. friends, work or GP. The willingness to try new approaches is visible in their ongoing attempts to successfully live with the impact of this condition.

### ***The narrative of participant 1.***

P1 is a white female who was 33 years of age on entry in to the study. She was working full-time in a clerical/administration role and was living with a same sex partner. There were no children in the household. She and her partner were able to both plan and be spontaneous with respect to going to work, doing household chores and socialising.

P1 had experienced musculoskeletal symptoms (pain felt in her back and hip) for 5-6 years prior to her diagnosis. She had self managed this as she felt that the symptoms were not out of the ordinary and would resolve with usual self management strategies of painkillers and rest. 6-12 months prior to diagnosis she had begun to complain of tiredness, that did not respond to rest, and worsening pain for which she was unable to provide a rational explanation. X-rays were able to provide an explanation for the symptoms in her back. However further investigation (blood tests) by her GP for her tiredness had been unable to identify a potential cause. Routinely she rarely consulted her GP and her GP initiated an early referral to Rheumatology for consideration of the diagnosis of FMS.

With the discussion of a possible diagnosis P1 began to self resource information on FMS.

She was hopeful that doing so might provide her with advice on treatment that would bring about a resolution of her symptoms.

"Well once I knew what was wrong I read quite a lot of books on it, got books out of the library. And I thought the symptoms just match up and with a bit of forewarning

there may be stuff I can do before I go. Because he said he'd refer me to the Consultant but I didn't know how long that would take. As it was it was several months and I thought I don't want to be off work and doing nothing while I wait for this appointment" Participant 1

Upon diagnosis she reconciled herself that that complete resolution was unlikely. Instead there was the hope that being better informed would help her to manage her condition more effectively. She wanted to reject the identity of being a person with FMS and wanted her identity to remain as it had pre-illness/pre-diagnosis and this is highlighted in concerns she had about going to a support group where complaining about symptoms was the dominant feature:

"For these people (the FMS support group) it becomes almost like your whole life is this illness rather than this is a bit of my life and the rest of it goes on" Participant 1

A place on the PMP was cancelled after she sought advice and treatment privately from a homeopath. Acknowledgement was made that the 'active' treatment from the homeopath might have been helping with her symptoms; she also highlighted the important role that talking and learning to manage her stress through these consultations appeared to be having. A combination of the homeopathy, reading of literature regarding FMS and the research study caused her to begin to question the role that previous abuse might have had in her condition. At the end of the period of study she was contemplating confronting her abuser. She expressed hope that doing so might alleviate some of the potential psychosocial influences on her condition.

P1 utilised a number of strategies at home and at work to attempt to minimise the symptoms and effects of FMS. These changes were usually the result of discussion, negotiation and problem solving with her partner in the first instance. FMS had caused changes in both of their lives, primarily as a result of the physical impact of the symptoms of FMS on performing as previously at home and work. Rather than allowing the effects of FMS to dictate what she/they were able to do they endeavoured to determine what she/they could do, and thus control FMS.

"This condition hasn't just affected me, its affected both of us. And we don't go out a lot, we do a lot together. So it just makes sense that if there's a problem, like work, we just sit down and try and sort it out together. Because if I work less I might be able to do more at home, but we'll have less money. We have to think it through and see what works best" Participant 1

Further examples of this included:

- Reducing hours of work from full-time to part-time/flexi-time
- Writing a letter to work colleagues detailing: what her condition was, the limitations it posed, the impact it might have on her abilities to fulfil previous duties and strategies she had put/was putting in place to ensure minimal disruption
- Changing their financial outgoings so that P1 was able to work less hours without being stressed about the financial impact of this
- Placing greater emphasis on socialising at home than going out, be this just the two of them or with friends

Concerns were raised that FMS was treated differently to other musculoskeletal conditions and that if the diagnosis had been different ongoing support would have been available at the hospital and review appointments made. However, P1 appeared to be confident of the ability of her GP to be aware of new advances in the management of FMS and this came from the early referral and diagnosis. There was a belief that if new treatments became available they would be implemented if appropriate.

### **Quest (active disengagement)**

In the quest active disengagement narrative there is a desire by the individual to minimise the symptoms and effects of FMS, mirroring the objectives of the active engagement narrative. In contrast these individuals are characterised by their attempts to disengage with treatment and adopt strategies whereby they disengage from their former lives. This is often in conflict with advice offered by medical professionals and other external agencies e.g. works and pensions.

### ***The narrative of participant 11***

P11 is a white female who was 58 years of age on entry into the study. She was divorced and lived alone; marital breakdown was the result of abuse. She had 3 grown up children one of whom was tetraplegic: none of them lived locally. She was not working at the point of entry into the study but had previously worked both as a state enrolled nurse and care home manager.

At the point of diagnosis P11 had been experiencing her symptoms for approximately 5 years. This had coincided with her marital breakdown and decision to finish work as a result of stress. She described non-specific pain that appeared to have begun for no apparent reason. She had consulted her GP on numerous occasions and described having a medical file that was "thick": this was a consequence of these problems but also IBS and managed cardiac problems.

Initially she had felt that her problems were psychological and this was reinforced when she initially saw Orthopaedic Consultants who failed to make a diagnosis. Diagnosis by the Rheumatologist reassured her that nothing was wrong and that it wasn't "hypochondria". On being diagnosed she actively resourced information about FMS and used this to tell people about the condition, the symptoms it caused her and what she was no longer able to do. Requests for help were justified by reminding and reinforcing her diagnosis and the limitations it imposed.

Diagnosis allowed her to seek an appeal against a previous decision regarding accessing disability living allowance. She considered having a medical diagnosis legitimised her claim and she was successful in gaining this benefit and this is highlighted in her first interview:

"I thought I know I'm entitled to DLA because of all this rubbish (*her symptoms*) and I couldn't get it because nobody had a firm diagnosis. They thought I was a fraud. But now I've got the DLA because I could put it, the fibromyalgia, on the form where it asks what's wrong with me"

Receipt of this benefit further reinforced her identity as someone with FMS and she utilised it to justify disengaging with treatment and activities of daily living. Examples of this included:

- Declining a place on the PMP on the grounds that she wouldn't be able to get there and would be unable to participate given the pain and fatigue she experienced.
- Paying for a cleaner and arranging for shopping to be delivered from her local corner shop. If her symptoms were especially severe she would ring the corner shop and ask them to deliver sandwiches as on these days she felt unable to prepare food.
- Paying friends and neighbours to do small jobs for her e.g. go to the post office.

Disengaging with activities or attempting to do them in a more passive way provided evidence of the strategies she adopted to cope with her condition. This is evidenced when asked about whether she has been referred for any treatment:

"They've asked me to go to physio or this pain management. But I mean how can I. Sometimes I'm good sometimes I'm bad. And how can I get there and do the exercises. I mean they know what's wrong with me but don't seem to understand what

it means. I don't want to be like this but if I went, that would be it, I'd be done for the day. So it's better I stay here, where I've got everything I need" Participant 15

She wanted to be perceived as 'disabled' and adopt the identity of someone with FMS. When other people or agencies tried to engage with her to increase her activity levels or participation in society she became frustrated and angry. These attempts were seen as potential sabotage to the life she had renegotiated to live with her FMS.

A recurring example of this was displayed in the repeated attempts of the Department of Work and Pensions to meet with her. She felt that they did not understand her condition in both expecting her to be able to make appointments to meet with them or return to work. In not working she was able to manage her symptoms and impact of FMS in a way that was acceptable to her: she felt they lack empathy and failed to show any appreciation of why they might want to work with her to enable her to return to work, of some sort.

There was limited evidence of social support and socialisation outside of the home. Family did occasionally visit her but she felt they discredited her condition and rarely offered any support. A few friends visited and she highlighted how they understood how she felt and her physical restrictions.

"I've got a few friends who come round. They know what it's like, they've seen me at my worst. They know I can't come out to them: it might be a bad day and I'd have to cancel or I might not be able to get back. So they visit and if I need something doing they will. The other day I'd spilt something on the floor and couldn't clean it up. So when he (*her friend*) came round I told him and he just did it" Participant 15

They reinforced and encouraged her disengaging behaviours: they always came to see her and did not expect her to meet them, either in their homes or elsewhere. Friends who had been unable to 'see' things from her perspective no longer visited.

### **Chaos**

The chaos narrative is characterised by a loss of control and the perspective that life is never going to get better. The narratives frequently highlight a disengagement with life: this is not an active choice (quest-active disengagement) but a product of what life and the effects of FMS have brought about. They feel disempowered to have any effect upon this, choice is absent from their lives and they are at the will of the body and society. This narrative is often characterised by an absence of social support and an ability to be heard by others.

### ***The narrative of participant 13***

Participant is a white female who was 45 years of age on entry in to the study. She was divorced and lived alone: marital breakdown had occurred after the onset of her symptoms. She had 2 children who were grown up and had left home and saw one of them regularly. She was not working and had recently moved home due to her marital breakdown.

Participant 13 had experienced her symptoms for 2 years prior to being diagnosed with FMS. At this point she was married and working full-time in an administrative job. When her symptoms first began she thought they were the normal symptoms of getting older. At times they were so bad they prevented her from going to work but at this stage a day or two off work would improve things so she could return. When this became less effective she began to seek help and advice from her GP. Her symptoms increased and failed to respond to management strategies that were tried. In addition investigations were unable to identify a cause. She was no longer able to manage her symptoms by taking time off work and had to finish.

The increasing musculoskeletal pain combined with growing fatigue began to impact on physical intimacy with her husband. He appeared unable to reconcile the invisible and variable nature of her symptoms with a lack of explanation or diagnosis. She described how he began to feel "rejected" and this eventually led to him leaving her, an event she became tearful when describing in her first interview:

"He just didn't understand. Saw it personally, that I was rejecting him. I couldn't get him to see how bad I was, how bad I was feeling. You see there's nothing is there (*pointed at her body*). And one day I'm okay and the next, wham. So he thinks it's about him, and it's not it's about me. So you see the GP, and the tests are normal. And they don't know what's wrong, so he starts not to believe you, to wonder why you're behaving like this. And so you end up like this on your own" Participant 13

This was followed by a breakdown in the relationship with her son. He could not understand the nature of her symptoms either, and empathised with his father. He continued to visit but this was infrequent and often resulted in an argument about the lack of understanding or sympathy for her situation. She couldn't change how he felt about her and was distressed that by no longer seeing him she was denied regular access to her grandchild. This was in contrast to the relationship she had with her daughter who regularly visited, offered support and listened to her.

Diagnosis with FMS provided reassurance that nothing serious was wrong. However, greater impact was felt by the knowledge that FMS was a condition with an unknown

cause and no curative treatment was available. This compounded feelings of losing control and being unable to influence how her body felt. Further reinforcement of this came with growing biographical disruption: marital and family breakdown combined with loss of employment causing increasing social isolation and decreased social support.

"I went to see the specialist and he told me what's wrong but there's nothing they can do about it. They've given me some tablets but they don't help. And I can't go to work and I can't go out. I've got no money and wonder how I will keep paying the bills and some days you can't go on like this. There is no way out of this, so it makes you think about ending it. What's the point anymore?" Participant 13

It became difficult to visualise any likelihood of being able to restore life to an acceptable way of being and she became suicidal, resulting in referral to a Psychologist during the course of the study.

She attended the PMP and was able to describe and understand the potential benefits of some of the strategies that had been discussed. Unfortunately she was unable to see how she could engage with them: this also applied to the other patients she had met on the programme.

"It was good going to the group, to see others like me, and hear what they were doing. And the exercises and relaxation that helped. But it's hard to keep doing it on your own, and you don't have the hot pool (*referring to hydrotherapy*). I mean the local pool that's cold and I couldn't get there anyway. *Another participant* has offered to go, you know a few of us to meet, go for a swim and a coffee. But I can't get there and she will get me, but that's not fair is it. I mean she's as bad as me. So it's best that I stay here" Participant 13

She had enjoyed meeting others in a similar situation but rejected any attempts to maintain contact once the programme finished, even when they offered to come and see/contact her.



